The Diagnosis and Management of Endometriosis with Food:

A Journey

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Abstract

Endometriosis is a debilitating and all-consuming disease which effects females of reproductive age. Symptoms can include chronic pain, nausea, headaches, body aches, and digestive and urinary issues. Endometriosis is unpredictable, as while there are four stages of the disease these stages often do not reflect the symptoms the women experience. Endometriosis is difficult to manage due to the unique symptom presentations and where the medical professionals' focus is primarily on pain management with medication. Women often resort to trialling other strategies to try to mitigate the impact this disease has on all areas of their life including social life, work and education, relationships and hopes for the future. The use of diets and food is one strategy that has helped some women to manage their symptoms, but these food restrictions also make life more difficult in terms of maintaining relationships. The aim of this study was to explore women's experiences of living with endometriosis with a focus on how women used food and diet. The feminist approach of this study privileged the women's voices as experts in endometriosis. This research utilised two semi-structured interviews and food diaries to explore how eight New Zealand women live with endometriosis. Thematic analysis revealed six themes; impact on life, lack of education, mental and emotional impact, judgement/perceptions, community, and learning moments. All the women had trialled diets in an effort to take back control, resist the medical dominance in treatment plans and feel healthier. The women talked of the sacrifices they had made by being on diets such as not attending social events as there would be no food to eat, but where they also discussed sacrificing their health and at times causing flare-ups by abandoning their diets so they could socialise. While the women critiqued medical professionals for their lack of knowledge and education, they also viewed themselves as lucky and discussed positive experiences of living with endometriosis.

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just through conversations with friends and loved ones, thank you, every little bit counts and we must provide the knowledge to help future generations, to prevent the bad experiences that many of us have endured. Thank you for being strong and thank you for sharing.

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Chapter One

What is Endometriosis?

Endometriosis is a pervasive chronic inflammatory disease which affects approximately 176 million women worldwide, including 120,000 women in New Zealand (NZ) (Endometriosis New Zealand, 2019a). Endometriosis occurs throughout the entirety of a women's reproductive years, and whilst there are tools to help manage the symptoms, there is no cure (Endometriosis New Zealand, 2019a). Endometriosis is when tissue similar to the uterine lining, known as endometrium, is found outside of the uterus growing on other areas throughout the body, including but not limited to the pelvis, ovaries, bowels, and in rare cases it can also grow on the lungs (Endometriosis New Zealand, 2019a). Despite the endometrium growing in unexpected places, the tissue still reacts to the menstrual cycle and can cause fluctuations in hormones, particularly oestrogen (Huntington & Gilmour, 2005). This means that these cells build, shed and bleed as they would within the uterus, causing internal bleeding, inflammation and pain (Huntington & Gilmour, 2005). Endometriosis New Zealand (2019a) explains that these cell growths can cause cysts which can rupture, and if found on a woman's ovaries this can cause fertility issues. Adhesions are also very common with endometriosis, where fibrous scar tissue can develop because of the disease itself, or as an effect of laparoscopic surgery used to diagnose the condition. Adhesions cause different organs to fuse together, again leading to severe pain and inflammation (Endometriosis New Zealand, 2019a). Further, adenomyosis is where endometrium is found within the muscle tissue of the uterus and is hypothesised to be caused by surgical procedures, causing similar symptoms as endometriosis (Abbott, 2016). As such, when endometriosis symptoms are present, adenomyosis should also be considered.

Upon diagnosis, women will be classified as having endometriosis at one of four possible stages that do not relate to the intensity, severity or frequency of symptoms. Rather, the classifications relate to the "location, amount, depth and size of the endometrial tissue" (John Hopkins Medicine, 2019) and the consequent physical issues that accompany it, such as adhesions, blockages of fallopian tubes and any cysts that may be found (Johns Hopkins Medicine, 2019). The stages range from stage one- minimal to stage four- severe (Johns Hopkins, 2019).

How does it present?

Endometriosis symptoms vary in severity and intensity from woman to woman with a myriad of presentations (Motashaw & Dave, 2012). Endometriosis New Zealand (2019a) states the key symptoms of endometriosis are intensely painful periods (clinically known as dysmenorrhea), painful sexual intercourse (dyspareunia), and fertility issues. Another common symptom that can be experienced is abdominal and pelvic pain, not only during a woman's period but also at other times throughout their menstrual cycle. Digestive problems including diarrhoea, constipation, bloating, and pain whilst urinating are other common symptoms of endometriosis (Endometriosis New Zealand, 2019a). Additional symptoms include fatigue, back and muscle pain, headaches and migraines, premenstrual syndrome (PMS), intermittent bleeding between cycles, and abnormal periods where sometimes bleeding is continuous or in contrast very irregular, often ceasing for months (Endometriosis New Zealand, 2019a). The complexity of the symptoms and disease can make diagnosis and treatment complicated and time consuming, this is because of the many possible differential diagnoses (Vannuccini et al., 2017) which also present with similar symptoms.

There are conflicting messages and medical information surrounding both the causes and treatments of endometriosis. Women, from as early as the 1960's were seen

as being the cause of their own illness (Shohat, 1998). Doctors believed fertility to be compromised in women with endometriosis because women put their careers first and delayed when they first tried for children (Shohat, 2006). This is clearly a myth as young teenage girls are also suffering with the disease, but it does illustrate the lack of education and knowledge about endometriosis even with medical professionals (Shohat, 2006). This dated perspective is still hinted at today, with many doctors still incorrectly prescribing pregnancy at a young age as a cure for endometriosis (Shohat, 1998). One of the problems is that there is still no known cause of endometriosis. There are theories such as the transplantation theory, where it is believed that the cells from the lining of the womb travel via retrograde menstruation (menstrual blood travelling back through the fallopian tubes) to other areas of the body where they settle and begin to react as they would in the womb (Endometriosis New Zealand, 2019a). Borghini et al. (2020) discuss another theory about environmental pollutant exposure being considered as a possible cause for endometriosis, where heavy metals in particular are known to cause disruption in oestrogen. Women exposed to the element Nickle is one such metal, particularly with those who are sensitive to it (Borghini et al., 2020). However, there is no clear answer as to what causes endometriosis.

Journey to diagnosis

Just a bad period

Internationally, the average length of time to diagnosis is eight years (Endometriosis New Zealand, 2019a). This is in part because of the portrayal of menstruation in society, where pain is an accepted part of being a woman, and painkillers, opioids and anti-inflammatory medications are endorsed in the management of pelvic pain (Markovic et al., 2008). Markovic et al. (2008) describe that because most women are able to manage their period pain with non-prescription drugs, this

creates the illusion that women should not have a complaint regarding their periods. Women are portrayed in the media—including in advertisements for feminine hygiene products—as being happy, carefree and able to control their menstrual symptoms to fully participate in society (Markovic et al., 2008). For women with endometriosis all of these factors can lead to the normalisation of severe period pain and delays in diagnosis. This can then lead to a worsening of symptoms, the development of infertility and a diminished quality of life (QoL) (Manwaring, 2018). Furthermore, due to societal attitudes that period pain is normal, women often find it hard to distinguish between 'normal' symptoms of the menstrual cycle and anything abnormal, often living with extreme levels of pain and discomfort (Manwaring, 2018).

Soliman, Fuldeore and Snabes (2017) explored whether the average length of diagnosis for endometriosis of nine years was still current in the USA. Soliman and colleagues conducted an online cross-sectional survey in the USA with 638 respondents. They found that the average length of diagnosis from onset of symptoms in the USA was only 4.4 years, which the authors attributed to an improvement in both patient and doctor education surrounding endometriosis (Soliman et al., 2017). Hudelist et al., (2012) found the average length of time for diagnosis is significantly higher in countries such as Germany and Austria where diagnostic delay for endometriosis is 10.4 years. Social factors likely attributed to this, such as with perceptions of the menstrual cycle and endorsement of hormonal contraceptives, and the expression of negativity and shame that appeared pervasive for these women. However, it should be noted that this sample of participants were all patients who had been surgically treated, which could have contributed to the length of diagnostic delay (Hudelist et al., 2012). This finding does demonstrate how cultural understandings of women's health and reproductive issues influence endometriosis. This was highlighted in a study by Kundu et al. (2015)

who explored women's experiences with endometriosis in Germany, finding many participants believed a key reason for delayed diagnosis was doctors' lack of information and being unfamiliar with the disease. Kundu and colleagues argue that better education would help to prevent delayed diagnosis from multiple referrals, unnecessary testing and poor overall management of such a chronic illness (Kundu et al., 2015). Both the cultural understanding of women's health and the medical system influence how this condition is diagnosed and treated. But what does seem to be consistent across countries is the substantial barrier surrounding gaining a diagnosis of endometriosis, which is the limited knowledge surrounding the disease and the mis-information that is pervasive both within society and medical professions (Kundu, Wildgrube, Schippert, Hillemanns & Brandes, 2015).

In addition to the lack of education and myths of women's health issues the presentation of endometriosis symptoms are so variable and more often than not complex, leading to difficulties regarding diagnosis of the disease (Bloski & Pierson, 2008). Every endometriosis presentation is different, which provides a challenge for medical professionals (Denny & Mann, 2008). The first challenge for a physician is deciding whether the presenting symptoms are a normal part of the menstrual cycle or something more serious (Denny & Mann, 2008). This highlights how the training of doctors, the medical system's approach to women's health issues and user pay systems can impact on the diagnostic process.

Diagnosis in New Zealand

In New Zealand, as with many other countries, the first point of call is the family general practitioner (GP). Many women with endometriosis express dissatisfaction with their GP, expressing that they were not listened to, and as a result had to endure disbelief and doubt around their experience of pain (Denny & Mann, 2008). Women

subsequently had to persevere and harass the physician to take them seriously (Denny & Mann, 2008; Whelan, 2007). Day (2012) explains that this can be traced throughout the history of women's healthcare where 'hysterical' women were once the explanation for any abnormalities with women's health. This has progressed to blaming women for dramatizing personal and emotional issues and manifesting them as physical issues. Rather than having something medically wrong with them, depression and anxiety are often blamed. Furthermore, because of the subjective nature of pain and the invisibility of endometriosis, interpretations of women's experiences of pain are often subdued by medical professionals who often disagree with the level of pain that a woman claims to be experiencing (Day, 2012). This may be because medical professionals tend to neglect the context within which the patient resides (Eposito, 2014), including their social and personal lives, pain tolerance, and the social constructions and expectations surrounding these (Day, 2012). With these combined factors, women with endometriosis are often viewed as being dramatic about their extreme levels of pelvic pain, or are viewed by medical professionals as drug-seekers (Day, 2012). Women are therefore expected to act in a socially acceptable way regarding period pain and their presentation of this to medical professionals, and should listen to doctors' advice even if the doctor is disbelieving (Eposito, 2014). Because of this, in seeking an endometriosis diagnosis, women must defy societal standards and become advocates for themselves, pushing past expectations to get the needed attention.

When a GP decides that the presenting problems are something to investigate further, a process of elimination begins. A disorder that is commonly mistaken for endometriosis, due to the sharing of certain symptoms is irritable bowel syndrome (IBS), commonly known as an inflammatory gastrointestinal condition that causes chronic pain and disturbed bowel movements (Spiegel, Farid, Esrailian, Talley &

Chang, 2010). However, it should be noted that although IBS is used as a medical diagnosis, 70% of health care professionals believe IBS to be a diagnosis of exclusion, meaning that the diagnosis is only made upon a process of elimination (Sood, Foy, & Ford, 2017). This is because there is no specific test for IBS, so diagnosis is based on presenting symptoms and the absence of any abnormal test results (Spiegel et al., 2010). IBS is therefore a condition that has become highly controversial in the medical field as it is currently still used as a diagnosis and promoted in guidelines as *not* being a diagnosis of exclusion, but many believe it should no longer be used as it is a "waste basket" (p. 382) for a variety of symptoms that are most likely misdiagnosed illnesses (Camilleri, 2012). As such, IBS appears to be another way that physicians can dismiss women with endometriosis, grouping them into a diagnostic group with no real identifiers, and which clinicians view as being largely psychosomatic (Sood et al., 2017).

Another factor complicating diagnosis is that endometriosis and IBS symptoms can be similar and can present at the same time leading to confusion about which disease a woman is presenting with (Viganò, Zara & Usai, 2018). Women with endometriosis are 2.5 times more likely than a woman without endometriosis to have IBS symptoms, especially if endometrium is found on or around the bowel (Schomacker, Hansen, Ramlau-Hansen & Forman, 2018). This often first leads to an IBS diagnosis, due to the ease of which it can be diagnosed in comparison to endometriosis. Sinervo (2013) explains that this confusion in diagnosis occurs because bowel symptoms (such as diarrhoea, cramping, painful bowel movements, constipation, bloating and nausea) are very common in women with endometriosis. These symptoms indicate issues with the bowel, so a doctor or gynaecologist will usually refer their patient to a gastroenterologist to rule out any serious bowel disease such as Crohns or

colon cancer, and then more likely than not diagnose them with IBS (Camilleri, 2012). Women with an IBS suspected/confirmed diagnosis typically endure invasive and intimate procedures such as colonoscopy and endoscopy, with no consideration that the bowel symptoms could be due to endometriosis (Camilleri, 2012; Sinervo, 2013).

When an individual's GP establishes that their symptoms are abnormal, and differential diagnoses have been ruled out, the individual will then be referred to a gynaecologist through the District Health Board (DHB) (Endometriosis New Zealand, 2019b). Gynaecologists assess the individual and their symptoms, and perform tests to establish whether they fit the criteria for needing diagnostic surgery (American Society for Reproductive Medicine, 2012). Pelvic examinations can provide insight into whether an individual has endometriosis, as sometimes there are visible endometriomas or cysts. However, it should be noted that although an internal examination may raise no suspicion of endometriosis, it is still possible to have the disease (American Society for Reproductive Medicine, 2012).

The only way to give a definitive diagnosis of endometriosis is via a laparoscopic surgical procedure, which is not only used for diagnostic purposes but for the ablation or excision of the endometriosis (Duffy et al., 2014). A laparoscopy is surgery where the patient is given a general anaesthetic, and a laparoscope is inserted through the belly button in order to view organs endometriosis may be growing on (Endometriosis New Zealand, 2019b). Ablation is the burning of endometriosis with a laser, however this only treats surface endometriosis (Haislet, 2019). Excision is the cutting of endometriosis from the tissue as it is believed that endometriosis is deep and extensive (Haislet, 2019). The methods used today are based on gynaecologist preference. Neither form of laparoscopy cures the individual, nor does it restore fertility or eradicate symptoms associated with the disease, but it has been known to make

symptoms more manageable (Fjerbaek & Knudsen, 2007). In addition to this, it can help reduce a woman's subfertility to give them an increased chance of being able to conceive (Duffy et al., 2014). The benefits of the surgery, such as reduced pain and nausea, can take weeks to months to feel after the surgery, and in some instances the symptoms worsen before improving (Endometriosis New Zealand, 2019b).

In New Zealand, there is high demand placed on the public health system because it is a free option, straining health resources available (Bohmer, Pain, Watt, Abernethy & Sceats, 2001). As a result, wait times can be long and access to health services are monitored, with the use of these services prevented at times (New Zealand Now, 2019). The use of a medical specialist within the public sector is also free and so the use of the public system is valued despite long wait times (New Zealand Now, 2019). With a disease as complex as endometriosis, a woman is typically referred to several specialists before they get to see a gynaecologist because of the many different diagnoses that can be attributed to their symptoms (Prentice, 2001), and so the ability to access these services free of charge is an incentive for NZ women. However, this likely adds to the length of time it takes to receive a diagnosis.

Once referred, within each specialist field in the public sector there is a waiting list (Southern Cross Health Insurance, 2019). The length of time a patient waits depends on the presenting symptoms, the severity and intensity of those symptoms, and the level of demand that is currently placed on the particular specialist field (New Zealand Government, 2020). Unfortunately, the public health sector in NZ has long had significant demand and pressure on their resources, and so for non-emergent diagnostic or non-acute surgeries the wait is typically substantial further adding to diagnosis delays (Mcleod et al., 2004). The Canterbury District Health Board (2018) reports the average time it took for a patient to be seen by a gynaecologist was 256 days in 2018, which was

a lengthier time than those waiting to be seen by oncologists (48 days), neurologists (163 days), and cardiologists (228 days). This is despite the District Health Board aiming to have an appointment scheduled within four months (Ministry of Health, 2016).

Rather than facing the difficulties of the public health system, the private health care system and specialist care can be accessed; however, this is expensive. But if an individual has health insurance to cover the cost of specialist appointments and testing then this is a viable option (Endometriosis New Zealand, 2019b). Those who have health insurance also have the added ability of being able to choose their own specialist and book their own appointments (Endometriosis New Zealand, 2019b). The percentage of those covered by health insurance has decreased in recent years. In 1996-1997, 40% of adults and 31% of children had health insurance, whereas in 2011-2015, 35% of adults and 28% of children did (Ministry of Health, 2016). Further, those who have health insurance are typically employed, highly educated and on a higher income than those without health insurance (Blumberg, 2006). Only 14% of those insured are from an ethnic minority, such as Māori and Pasifika (Blumberg, 2006). This indicates that employment and money are barriers to accessing both health care and health insurance. In NZ this is an important reason as to why the health statistics for ethnic minorities are so different to the Pākehā (white) population of NZ (Mcleod et al., 2004). Māori and Pasifika peoples are less likely to have health insurance (Mcleod et al., 2004) and as such there may be detrimental effects when it comes to gynaecological issues as they are less likely to seek out health care for sensitive and private issues (Marlow, Waller & Wardle, 2015). Marlow and colleagues found cultural practices and beliefs about sex, female hygiene and health, limited knowledge within communities and decreased access

to services because of language or cultural awareness, influenced whether Māori and Pasifika women accessed cervical smear tests.

Lastly, the pain is very subjective and further education and information is needed when assessing pain. Women with endometriosis frequently visit emergency rooms in severe pain where a numerical scale (1-10) is used for assessment (Norman, 2018). However, as Norman (2018) explains, scales only take into consideration the intensity of the pain whilst ignoring descriptive and contextual factors. Also, emotions go hand-in-hand with pain, with certain moods and emotions exacerbating pain and vice versa, meaning a patient having to give a definitive number regarding their pain is difficult and confusing. This means the full picture is not taken into consideration, rendering the scale unhelpful as a diagnostic tool (Norman, 2018). Women often find it hard to explain their pain and when doctors cannot find the source of it they regard women as malingering and perceive them to be hypochondriacs or drug-seeking (Norman, 2018). As the primary symptom, pelvic pain, is subjective and therefore not directly observable by physicians, women are often contradicted and patronised (Whelan, 2007). Whelan (2007) suggests that medical literature tends to depict women with endometriosis as being agitated, unreasonable and dramatic, and explains that women are merely experiencing the natural, but at times, painful menstrual cycle. This leads to a patronising and contradictory attitude from doctors, and suggests that they need further training and understanding, and where the tools used to assess pain need to be substantially improved. All in all, women's perception of doctors is that they have limited knowledge regarding female health problems and endometriosis (Whelan, 2007).

Support groups

Length of time to diagnosis and lack of understanding and cure has led women to search for their own sources of information regarding endometriosis. Support groups and forums are one of the most common and easy to access platforms (Whelan, 2007). These social support groups are sought after in an attempt to understand more about the health issues that an individual or their loved ones are experiencing, and to meet people in a non-confronting environment who are also experiencing the same issues (White, 2001). The information that can be accessed includes mental and emotional support from individuals who are going through similar experiences, and the acceptance and allowance of individuals as experts of their health conditions and thus can share their thoughts and actions to help others (Whelan, 2007). Numerous individuals report that they can reach out when experiencing negative emotions in reaction to barriers or bad days, but also in times of victory or when having a good day (Barak, Boniel-Nissim & Suler, 2008). Support groups can give a sense of belonging and promote wellbeing through the immersion in a positive community (Barak et al., 2008). Barak and colleagues (2008) suggest the main reason for the use of support groups is for people to connect with others who have empathy towards them and can understand their experiences. Online support groups are a beneficial platform for women with endometriosis as they often feel they cannot talk with friends and loved ones about endometriosis to their fullest extent. Only other women with endometriosis know what they have been through (Barak et al., 2008).

Support groups create a shared narrative between women with endometriosis and bands them together as a community with shared experiences, beliefs and relationships (Whelan, 2007). This is especially important for women who have been confronted with disbelieving doctors, friends and co-workers who do not believe the

severity of their symptoms and which consequently can lead women to feel lonely and isolated (Hållstam, Stålnacke, Svensén & Löfgren, 2018). Support groups are a buffer for this. Many people, including other women, claim to not have any knowledge of endometriosis prior to either being diagnosed with the disease or knowing someone who has developed the disease, which indicates the lack of acknowledgement and education of this disease in society (Moradi, Parker, Sneddon, Lopez & Ellwood, 2014). Support groups are therefore important as a means of accessing information and empowering individuals to take action and control over their health by sharing stories and knowledge (White, 2001).

Endometriosis: a gendered disease

Endometriosis is a debilitating and stigmatising disease due to the social discourse and perspectives surrounding the symptoms and what is known (or not known) about the disease, with women often disparaged and seen as overly dramatic with bad periods (Seear, 2016). There are many taboos, misconceptions and myths surrounding menstruation, reproduction and endometriosis (Hummelshøj, 2005). These stem from society's perspectives and expectations on women's menstrual health and their ability to have children, where from a girls menarche they are typically celebrated as becoming a woman (Kaur, Kaur & Kaur, 2018). As such, endometriosis can be viewed as being unnatural and a hinderance to reproduction, due to the fertility issues that can accompany the disease. However, fertility issues do not occur for all women with endometriosis. More often fertility is decreased rather than defunct in every three to four women out of ten who have been diagnosed with endometriosis (Endometriosis New Zealand, 2019c).

Another factor that both enforces and is enforced by this lack of knowledge is that menstrual health is seen as a "women's problem" (Dudgen & Inhorn, 2004, p.

1388) and this is compounded as males tend to have restricted access to information about menstrual cycles, fertility and reproduction (Dudgen & Inhorn, 2004). As a consequence, half of the population does not know what is normal or abnormal regarding women's health. Puberty and reproductive information presented to boys is typically glazed over throughout their education and from their parents or not mentioned at all (Claussen, 2018). This is because of the importance that society and therefore school-based sexual health programmes places on women's sexuality, sexual health and fertility (Claussen, 2018). Further, boys tend to have an immature response to learning sex education in school, where they demonstrate a lack of interest and focus (Hurwitz et al., 2017). Men also do not have the same time pressure to reproduce as they have a significantly longer period of fertility (Dudgen & Inhorn, 2004). While reproduction and fertility issues are typically categorised as a problem unique to women these issues effect both males and females, as males cannot have children without women and vice versa (Dudgen & Inhorn, 2004).

There are variations in what women learn about menstruation and women's health and the amount that they can learn depending on the country, region and sociodemographic group they belong to (Sommer, Hirsch, Nathanson & Parker, 2015). However, all women appear to receive a code of conduct which they should enact when experiencing a period (Sommer et al., 2015). They should adapt to the role of secret-keeper, where other people should not know about what they are experiencing, and so they resort to concealing their pain, discomfort and necessary sanitary products (Sommer et al., 2015). Therefore, the way women typically act when they have their period reinforces the idea that men do not need to trouble themselves with learning about periods, where in turn males not having learnt about periods means that there is no understanding for their female counterparts. Mahon, Tripathy and Singh (2015)

describes how males voices are promoted and privileged above females, which has consequently led to the stigma, shame, taboos and secrecy surrounding women's menstruation and reproductive health.

The Lancet Child and Adolescent Health (2018) describes how young girls can find starting their menstrual cycle as embarrassing, disgusting and viewed as a weakness of becoming a woman. The dominant discourse for these young women is that the surrounding symptoms associated with menstruation including pelvic pain is natural, that pain is part of becoming a woman with the ability to bear children, and as such females must endure it. This then trivialises women having to suffer through periods and pelvic pain even when women have irregular and unusual periods characteristic of endometriosis (The Lancet Child & Adolescent Health, 2018).

The invisible nature of endometriosis means that if doctors do not believe or find a biomedical reasoning behind the patients symptoms, then they are silenced (Grace, 1995). Grace (1995) explored the disparities between NZ medical professionals and women with pelvic pain and highlighted that women who complained of pelvic pain were seen as neurotic and that the pain only existed in their heads. There is then a constant negotiation between the patient and doctor, where the patient has to argue that her pelvic pain is abnormal and requires further testing, and where the doctor has to attempt to treat the patient in a way that keeps them appeased but that is also ethical and that they can justify (Marchant-Haycox & Salmon, 1997). Burr (2015) suggests the voice of medicine is male and authoritative, leading to a loss of empowerment for women at their medical appointments especially if they are being seen by a male doctor (Burr, 2015). Medical professionals have more power, status and believability applied to their conclusions, whereas females' lived experience of their symptoms does not carry much weight in comparison (Burr, 2015).

In summary, the dominance and powerful positions that males encapsulate within the medical profession, both throughout history and presently, has led to health problems such as delayed diagnosis and poor treatment of women with endometriosis. Women are also more likely to be told that their symptoms are psychosomatic, and so are often referred to mental health practitioners rather than specialist doctors (Adler, 2017). This is believed to be because the medical profession has built its knowledge base around male physiology and male patients, and so when a female presents with something specific to women (such as endometriosis), it can take an extraordinarily long time to diagnose as the medical profession does not have the knowledge or the trust in the female patient and presenting symptoms (Adler, 2017). Stigma surrounding menstruation and the normalisation of pain for women also contributes to the delay of diagnosis and reinforces and is reinforced by sexism within the medical profession (Society for Women's Health Research, 2019). Other barriers to diagnosis is the lack of education on women's health problems and endometriosis plus diagnosis can only be confirmed through laparoscopic surgery. Women are also their own barrier as societal expectations and opinions promote the idea that these topics should not be discussed, and that it is unnecessary and attention-seeking to ask for help (Society for Women's Health Research, 2019). Women reinforce this social etiquette and are therefore disadvantaged when it comes to their health, as they will take some time to profess their need for help with anything related to women's health (Adler, 2017). Endometriosis is a gendered disease which is reflected in society through long waiting lists for gynaecological services, a lack of education within the medical field and in the general population, and a forceful focus on protecting the women's ability to reproduce. Management strategies further reflect these inequalities and are discussed in the next section.

Management of Endometriosis

This section will discuss the dominance of the biomedical model of management of endometriosis, which is viewed as best practice by medical professionals.

Medical management

The intention of the medical management of endometriosis is to suppress ovulation and to generate healthy hormone levels in the body in an attempt to control the growth of the endometriosis (Black & Fraser, 2012). The goal is to suppress and improve symptoms as the cause of the disease is still unknown, meaning there is no cure (Endometriosis New Zealand, 2019b).

Surgery. Laparoscopic surgery is not only used for diagnostic purposes but also as a way to manage endometriosis. Surgical treatment can be extremely effective for reducing symptoms such as pain, and to increase women's fertility if they are sub- or in-fertile (BPA, 2013). This improvement may not be felt for some time afterwards as laparoscopy is invasive, and the extent to which the surgeon excises or ablates the endometrium and surrounding organs depends on the severity of the endometriosis discovered during surgery (Endometriosis New Zealand, 2019b). It should be noted that the recurrence rate of endometriosis and its symptoms are high, with 10-20% of women experiencing the return of their symptoms within one year (Black & Fraser, 2012), and 50% within five years (BPA, 2013). These statistics reinforce why some women with endometriosis have multiple laparoscopic surgeries. If the endometriosis is too severe and pervasive, then more radical forms of surgery may occur, such as oophorectomy (surgical removal of one or both ovaries) or hysterectomy which depending on the severity is the removal of uterus, cervix, fallopian tubes and the tissue surrounding these (National Cancer Institute, 2019).

Hormonal suppression and management. The suppression of ovulation is a common method in attempting to treat endometriosis by inhibiting its growth (Endometriosis New Zealand, 2019b). The most common way to do this is through the use of combined oral contraceptive pills (the pill) which can help regulate periods and cause a decrease in negative symptoms associated with it, such as pelvic pain (Endometriosis New Zealand, 2019b). Women are typically advised to take the 21 day active pill, followed by the 7 day inactive pill to induce bleeding like they were having a normal period (Ministry of Health, 2017). However, most women with endometriosis are advised to take the pill either continuously, skipping the inactive pills every month in order to prevent having a period, or they take the pill semi-continuously, where they skip the inactive pills for either three or six months, and then take the inactive pills to break the cycle (BPA, 2013). Since the endometrium sheds and bleeds with the menstrual cycle, continuously using the pill means that menstruation stops and the endometrium should not spread further or respond by bleeding and shedding, and so should stop causing inflammation and pain in the body, reducing key symptoms of endometriosis (Family Planning, 2015). Other forms of hormonal suppression for endometriosis includes the Depo-Provera which is a form of contraception injected every three months (Pfizer Australia, 2016, and the Intra-Uterine Device (IUD) which is long lasting and inserted by a medical professional (Family Planning, 2019).

It is important to note that the use of contraceptive management such as the pill, Depo-Provera and the IUD do have adverse side effects. These side effects can include; break-through bleeding; nausea; abdominal cramps; headaches or migraines; breast tenderness, vaginal discharge, changes in libido (Cooper, Adigun & Mahdy, 2019; East, 2017), metabolic changes and weight gain, mood changes and gastrointestinal issues (BPA, 2013). Because of this and the fact that there is a large range of contraception

methods in today's markets, it is a process of trial and error in choosing the correct and most tolerable option for each individual (Stewart & Black, 2015). Women with endometriosis have more factors to consider in choosing a contraceptive pill such as decreasing symptoms, preventing growth of endometrium and maintaining their fertility, but it should be noted that if the right pill is found then it is a good option for endometriosis treatment as it can be stopped at any time (Weisberg & Fraser, 2015).

Pain relief medication. Medication, including pain relief and anti-inflammatories can be used to manage the chronic pain associated with endometriosis (Endometriosis New Zealand, 2019b). Simple analgesics such as paracetamol can be used for mild endometriosis or period pain, or in conjunction with other medications to help the pain caused by endometriosis, however they are not as effective as other options (Endometriosis New Zealand, 2019b). Endometriosis UK (2019) describes Non-Steroidal Anti-Inflammatory Drugs (NSAIDs) as being effective as long as taken as directed and prior to the start of symptoms. NSAIDs are mostly available over the counter at pharmacies and supermarkets and which include naproxen, ibuprofen, diclofenac and Ponstan amongst others (Endometriosis UK, 2019). Wood and Johnson (2011) outline the potential side-effects from taking NSAIDs such as nausea, vomiting, digestive issues, stomach upset and stomach ulcers. There is no conclusive evidence on the effectiveness of these over the counter medications in helping pain associated with endometriosis (Allen, Hopewell & Prentice, 2005), but instead opioids are commonly used due to the increased effectiveness of masking symptoms (Rosenblum, Marsch, Joseph & Portenoy, 2008).

Opioids such as tramadol, and opiates such as codeine, codeine-based medications and its stronger alternative morphine, have been viewed as the most effective medications to manage chronic pain (Rosenblum et al., 2008). Tolerance of

these drugs can occur if they are taken frequently, where dosages need to be increased for them to be able to work as they are supposed to, which can lead to an individual wanting to take other, stronger forms of medications such as morphine (Chahl, 1996). Side-effects of these drugs can include constipation and other gastro-intestinal issues, constriction of the pupils, difficulty breathing, drowsiness and dependence (Chahl, 1996). There often is a progression in women with endometriosis from analgesics to NSAIDs, then opiates such as codeine and tramadol, and in severe cases oxycodone and morphine (Fraser & Franzcog, 2008). It is beyond the scope of this thesis to list all of the possible medical treatments available but the list serves as an indication that pain relief is a big part of 'treatment' but the resulting side-effects mean there is both a positive and a negative to taking medications. There is no doubt that pain medications are a necessary part of endometriosis management.

Other management

Once women receive an official endometriosis diagnosis they typically take more responsibility and control over their disease and consequently how they manage their symptoms (Seear, 2016). Alternative and complementary treatments are often trialled and adapted, either in addition to or instead of medical treatments. Women often disregard medicine altogether because of the dissatisfactory and negative experiences they have had with doctors and their methods of treatment (Seear, 2016). This section will discuss some of these strategies.

Exercise and physical activity are viewed as not only being good for a person's overall health and wellbeing but as being beneficial when living with chronic pain such as endometriosis, where certain exercises could help manage the symptoms (Endometriosis New Zealand, 2019d). This is because exercise improves circulation within the body, ensuring that oxygen and nutrients are delivered to the necessary

bodily systems, releasing endorphins which can help to relieve pain and improve mood, whilst lowering oestrogen which is essential in reducing the inflammation and pain of endometriosis (Endometriosis New Zealand, 2019d; Stewart, 2019). Armour, Sinclair, Chalmers and Smith (2019) found women should start with low-intensity work-outs which can then be gradually increased. Women express that physical exercise can exacerbate their symptoms, which could be because vigorous exercise may cause pelvic muscle spasms, triggering a flare-up of symptoms (Armour et al., 2019). Exercises such as walking, swimming, yoga and pelvic floor physiotherapy have all been found to be helpful for some women living with endometriosis (Awad, Ahmed, Yousef & Abbas, 2017; Stewart, 2019; Stovicek, 2018). Exercise to help manage endometriosis should be done thoughtfully, in some cases with medical supervision or advice, and which may require trial and error to work out what is best.

Endometriosis has a profound impact on the body and many processes as the body is under a lot of strain in regard to immune functioning, development of hormones and protecting the body from inflammation and pain (Darling, Chavarro, Malspeis, Harris & Missmer, 2013). There is an increased amount of research suggesting taking vitamins and supplements can help with effects of endometriosis (Darling et al., 2013). Examples of supplements and vitamins that help with endometriosis include antioxidants such as vitamin C, E and zinc, which can decrease the sensory nervous systems response to pain (Santanam, Kavtaradze, Murphy, Dominguez & Parthasarathy, 2013). A literature review by Halpern, Schor and Kopelman (2015) of 113 articles found that women who had a higher intake of fruits, vegetables and whole-grains, as well as those rich in omega-3, vitamin D and resveratrol (amongst others) had the appearance of providing defence against their endometriosis. While this is promising there is no clinical evidence that supplements can prevent or slow the development of

endometriosis. However, eating healthy foods high in nutrients is beneficial for overall good health and there is some evidence that diet can help symptom management. Further research is needed in this area.

The above forms of self-management strategies are commonly used, however, there are many other alternatives and holistic approaches that can be approached, some of which shows significant improvement on endometriosis symptoms such as acupuncture (Xu et al., 2017), the guidance of a naturopath and the provision of naturopathic medicine (Reid, Steel, Wardle & Adams, 2019), Chinese medicine and hypnotherapy (Meissner, Böhling &Schweizer-Arau, 2010). It is often up to each individual woman to try (and pay for) these strategies as the best practice model relies on medication and surgery.

Role of diet in endometriosis. As there is often the misdiagnosis of endometriosis for IBS (Endometriosis New Zealand, 2019d), some women may make dietary changes prior to their endometriosis diagnosis in order to alleviate symptoms of what they are told is IBS (Ek et al., 2015). The similar pathophysiology between the two illnesses mean that the diets utilised to manage IBS have also been shown to aid in the management of endometriosis (Jankovich & Watkins, 2017). The main diet to improve IBS symptoms with endometriosis is the low Fermentable Oligosaccharides, Disaccharides, Monosaccharides and Polyols (FODMAP) diet (Endometriosis New Zealand (2019d). These are molecules found in food which are poorly absorbed by the body, travelling from the small intestine (where they should be absorbed) to the large intestine, where they act as a source of food for bacteria, resulting in inflammation and gastrointestinal symptoms (Shepherd Works, 2019). The aim of the low FODMAP diet is therefore to discover what foods cause inflammation and gastrointestinal symptoms and significantly reduce these in ones diet (Shepherd Works, 2019). Reducing the levels

of these foods can help control symptoms and ease management but does not eliminate them completely (Kortlever et al., 2016). On average, three-quarters of patients diagnosed with IBS find an improvement in their gastrointestinal symptoms with the implementation of the low FODMAP diet (Kortlever et al., 2016).

Both IBS and endometriosis are inflammatory conditions (Issa, Ormesher, Whorwell, Shah & Hamdy, 2016). IBS causes inflammation of the intestinal tract, and endometriosis causes cells to shed and bled in alignment with the menstrual cycle leading to inflammation, which when on or near the bowel can lead to significant gastrointestinal symptoms (Issa et al., 2016). This suggests that a low FODMAP diet could improve some of the significant and debilitating symptoms of endometriosis such as pelvic pain and gastrointestinal symptoms. This diet also provides knowledge to women about their sensitivities and how food impacts on their body, so that they can attempt to control their symptoms and improve their lives through making decisions surrounding food.

There are many types of food groups which could be impacting on the severity and frequency of endometriosis symptoms, but as mentioned every woman is unique and therefore foods will affect every woman differently (Velasco, 2019). It is therefore essential for women to discover their triggers and attempt to eliminate or reduce these foods if possible to help manage and improve their symptoms (Velasco, 2019). However this can be difficult for a woman to do on their own especially if food and nutrition knowledge is lacking, particularly when medical advice does not provide much support for dietary management of endometriosis unless the woman pays to see a dietician. Widdowson (2018) states that nutrition advice given to women with endometriosis should be tailored to their lifestyle, preferences, medical history, symptoms, ways they have been treated in the past and how they are managing their

symptoms now. Velasco (2019) describes the endometriosis diet which is an example of a lifestyle and diet change that can be implemented that is individualised, which consists of replacing inflammatory foods in the diet which triggers endometriosis symptoms with other food sources that do not, such as eating more chicken and fish over red meat, eating foods with natural sugars and drinking almond milk. However there is little reliable evidence or research on one specific diet that is helpful for endometriosis management. The research that does mention diet in relation to endometriosis usually covers diet and food as an aside without any detail. There are no qualitative studies to this authors knowledge that explores the lived experiences of women making dietary choices whilst living with endometriosis, despite the quantitative research indicating that there is a correlation between diet and symptoms.

There is a strong indication that because endometriosis is an inflammatory disease, food choices and diets which cater to this could have a significant effect on endometriosis by decreasing the frequency or severity of symptoms. However, the individualised nature of endometriosis should be highlighted, where even if food choices and diet can be utilised as a management tool, these would need to be uniquely catered to the individual as every women is affected differently by endometriosis and food. Food in relation to endometriosis is an area of research which is under-funded and under-researched, with the majority discussing causation and risk factors. It is important to understand how women are using food and diets in their self-management of endometriosis. There are two aspects to this. Firstly, food is more than just nutrition, more than just fuel for the body, but it is a socially constructed practice which is monitored through social perspectives and expectations (Delormier, Frohlich & Potvin, 2009). Within this study it has been shown that food is a way of providing nutrients to and benefiting women's bodies, and that the eating patterns and practices of a collective

group of people also have an effect on the women (Delormier et al., 2009). Both should be considered as food is a large aspect of socialising in today's society, and as such, being on restricted diets can impact the women's social functioning and activities (Delormier et al., 2009). Research has largely ignored this element of women's lives with regards to endometriosis, and so this study aims to address this. Secondly, there is very little qualitative research exploring self-management techniques over the course of time for women with endometriosis. This study therefore aims to investigate how women use food to help manage their endometriosis and its symptoms with an emphasis on getting lived experiences.

Chapter Two

Literature Review

This chapter will focus on qualitative studies which explore women's experiences living with endometriosis. There is limited qualitative literature on endometriosis but the little there is focuses on the symptoms that women experience, and the management of these symptoms. Women's voices and their stories need to be prioritised, shared and learned from. The interviews in this study aim to explore women's experiences with endometriosis and throughout the entirety of their journey, whilst also ascertaining how food choices and diet plays a role in their lives in terms of helping to manage their endometriosis. As such, studies which prioritise women's voices and experiences are discussed below. The chapter will conclude with an outline of this research including the research questions.

There is often a neglect of women's experiences and voices surrounding menstruation, reproductive health and endometriosis in particular (Huntington & Gilmour, 2005), which is peculiar as they are the ones effected by these processes. Qualitative research forefronts the women's stories to fully understand health issues like endometriosis. Only women with endometriosis can fully comprehend what it is like living with the disease. As such, the predominantly masculine medical field needs to be challenged after decades of imposing their masculine perspective of femininity, reproduction, and menstruation on society where the prominent opinion was that women were built around and effected by their ovaries (Roberts, Goldenberg, Power & Pyszczynski, 2002). Further, women have been shown to be increasingly judged and viewed negatively if there was knowledge of them menstruating both by medical professionals and the lay-public (Roberts et al., 2002). This is emphasised by the large number of male gynaecologists in comparison to females, where in areas such as

Northland, Gisborne and Southland having a male gynaecologist is the only option (FigureNZ 2020), and so once again the masculine perspective is promoted. Kupiec (2019) states that medical knowledge is often created and reinforced by men, imposing the information about one sex (male) onto that of another (female). This is particularly detrimental to women's health as medical clinical trials use a largely male population, and so medical knowledge disregards the health factors and issues which are specific to the female population (Kupiec, 2019). As a consequence there is a lack of knowledge and often incorrect information being given to women about endometriosis. Treatment for endometriosis centres around the misinformation on what constitutes normal menstruation, women as potential reproductive bodies and the desire to preserve this, and pain management rather than the multidisciplinary approach that seems more suited to this complex condition. There is a clear need to further the level of education of all medical professionals with conditions such as endometriosis.

Endometriosis is a disease which is highly gendered and sexualised where treatment for the disease is used in a way to protect a woman's ability to have a baby rather than to reduce pain and other such symptoms (Jones, 2016). This was supported in the study by Young, Fisher and Kirkman (2018) who conducted interviews with GPs and gynaecologists and found that the medical professionals highly endorsed the medical authority and biomedical perspective of the women as a reproductive and sexual body. Doctors frequently refer to women as being built for the purposes of providing sexual gratification for men and conceiving children. Further, the women who claimed that they were in too much pain and who challenged medical authority were labelled as difficult and hysterical (Young et al., 2018). Pelvic pain for women was seen as normal, so the doctors expressed the idea that the women experiencing this level of pain have psychological issues, and that they are catastrophising their symptoms to

appear more severe than they are (Jones, 2016). In addition to this, Jones (2016) also suggests that the highly masculinised medical profession neglects women's voices in favour of medical knowledge which was developed through a male's lens. Whilst medical knowledge is important, the dismissal of the perspective of the patient can be detrimental, particularly for women in the case of endometriosis (Young et al., 2018). Further, the neglect of women's experiences and the blaming on hysteria leads to a neglect of much needed medical treatment and causes other people to doubt the women as well (Jones, 2016).

Living with endometriosis

There is paucity of qualitative research looking at women's experiences of endometriosis with very few reviews. Young, Fisher and Kirkman (2015) conducted one of the few systematic reviews on qualitative studies about women's experiences with endometriosis and highlighted common themes between participants of different studies. The first is that symptoms are normalised by medical professionals, often in a condescending manner, claiming that women do not know what normal period pain feels like. This was partly blamed on the introduction of the oral contraceptive. The review also found that some women's symptoms were ignored and diagnosis delayed for a long period of time, until it began to affect their fertility. This indicates society's importance placed on women being able to have children and a neglect of other women's health issues in comparison. The review highlighted that many women were misdiagnosed, often with either IBS or with having mental distress. Doctors appeared to do this to provide a diagnosis, to have something to work with rather than perform extensive investigations, often plying women with painkillers and hormone pills to temporarily alleviate symptoms. Many other instances of inadequate medical treatment occurred in addition to these common and prime examples (Young et al., 2015). This

has led women to believe and to construct their own hierarchy of knowledge pertaining to endometriosis, with women with the disease being the most knowledgeable and so at the top, with research second and the medical profession at the bottom. What this review reveals are the issues facing women with endometriosis and how common these are across English-speaking countries and their medical systems, as this review looked at the United Kingdom, Australia, Canada, New Zealand and France (Young et al., 2015).

This research will use a feminist framework to privilege women's voices on endometriosis, so they can provide first-hand subjective experiences to better understand the disease and the impact it has on them. Hummelshoj (2017) states that endometriosis is a disease which can break the mind and spirit because of the variety and abundance of symptoms, the limited knowledge surrounding the disease, the myths, and the fact that there is no cure. All of these factors can adversely affect a woman's wellbeing and lifestyle (Hummelshøj, 2017). It is therefore important to explore some key studies that have used a feminist standpoint to explore women's lived experiences of endometriosis.

Huntington and Gilmour (2005) explored NZ women's experiences of living with endometriosis, focusing on pain. This study was approached with a feminist methodology, where it was described that women's relationships with the medical profession—especially with gynaecologists—can be tense. This tension they suggest is due to the masculinity immersed within the medical community. Huntington and Gilmour recruited eight NZ women from a support group for women with endometriosis. This research found that all women participating in this study experienced intense chronic pain, which was categorised into four main themes: "'a crippling disability'- manifestations of pain; 'it comes in waves'- the pain trajectory; 'I

put myself through it and nothing works'- intractable pain; 'it's either suicide or fight'- controlling the pain" (p. 1128). Women with endometriosis often suffer from extreme levels of pain from a young age and this research highlighted the difficulty pain and the disease caused in relationships, in their career, and in everyday decisions such as exercise and diet. A limitation of this study was that it does not go into detail about the ways women manage the disease but rather focused on experiences of pain and the effects on their lives, so the interviews and discussion focused on the management of the disease within a medical context. Huntington and Gilmour (2005) mentioned that methods outside the medical profession have not been investigated but are highly valued and that methods such as diet in relation to endometriosis should be investigated as this is a gap in the research.

Another more recent qualitative review of women's pelvic pain associated with endometriosis was conducted by Mellado et al. (2019). Mellado and colleagues reported findings about the huge impact pelvic pain has on women's lives, effecting their relationships and ability to live day-to-day. The authors discuss the psychological impact of the disease, which in combination with the pain can lead to a horrible cycle, where the women are trying to fix and maintain their physical, mental and emotional health (Mellado et al., 2019). This study, like that by Huntington and Gilmour (2005), demonstrates the complexity of endometriosis and its impact, where despite being a very individualised disease it seems to effect women in the same way—in every area of their life—which is very difficult for the women and their loved ones to cope with. There was brief mention in the review by Mellado et al. (2019) of self-management methods but this was not discussed at length. The reason women tried different management tools such as diet was to challenge the biomedical model and doctors' advice.

It is important to consider how cultural understandings and practices of menstruation influence women's experiences and how women use socially constructed self-management techniques. Wong, Ip and Lam (2016) interviewed Chinese adolescent girls with chronic pelvic pain. Females within Chinese culture are conservative and do not openly discuss sensitive and personal issues like menstruation, especially during adolescence when they are supposed to be maturing and taking on more responsibility. The girls in this study only hinted to their mothers through body language and facial expressions when they were in pain rather than verbalising the need for help. The study found that menstruation and pelvic pain was not openly discussed, even with medical professionals and that the girls resisted Western medicine, having more faith in advice from traditional Chinese medical doctors. Interestingly, this study highlighted the role of diet, with the girls describing limiting cold food and drinks and Liang foods such as tortoise jelly which is believed to extend duration of menstruation by increasing flow and exacerbating pain. They also consumed red date water and black hen soup which they believed would help pelvic pain, and they did no exercise during their periods, afraid they would worsen symptoms (Wong et al., 2016).

Gilmour, Huntington and Wilson (2008) also conducted research from a feminist perspective on the impact of endometriosis on women in their careers and social lives in NZ. The participants were eighteen women who identified as living with symptomatic endometriosis between the ages of 16-45 years, recruited from an endometriosis support group through the National Endometriosis Foundation in NZ. The three key themes were; "a secret little world: disclosing symptoms", "everything shut down: life interrupted" and "it's been a very hard journey but it's also been a doorway: emergent life" (pp. 445-446). Theme one raises the personal nature of disclosing symptoms to employers and colleagues. The nature of symptoms, ranging

from menstrual issues to bladder and bowel problems were difficult to raise. The women debated about disclosing this information to an employer due to a lack of understanding, and a feeling of pressure to discontinue working. The second theme highlights the participant's difficulties maintaining their lives with endometriosis, particularly when first experiencing the symptoms. This is because the physical symptoms such as extreme pain and fatigue often made it impossible to perform their work or school duties, which often led women to pause or cease activities in their lives, including tertiary education. Endometriosis also causes fear surrounding their health including worry about fertility, long term health and future ability to participate in and live their lives. This leads to the third theme which discusses the lack of a cure for endometriosis which results in this constant quest for women who are suffering to find their own methods to manage their disease, including through diet and exercise. This highlighted the lack of available treatments for the disease both within and outside the medical profession, and that women are often not given any advice about anything other than medication or surgery. Women referred to endometriosis as having "controlled their lives" (Gilmour et al., 2008, p. 446). Women therefore typically took back control through managing their disease, trialling self-management techniques and finding ways to cope on their own. This study briefly emphasised that diet and exercise are important but this was not explored in any depth (Gilmour et al., 2008). A limitation of this study is it only briefly mentioned potential methods to improve QoL for those women with endometriosis (Gilmour et al., 2008). This could be beneficial and valuable to women as they could implement these methods to improve and educate themselves about various influences on the condition.

Gilmour and colleagues (2008) were primarily interested in the issues surrounding disclosure of and management of endometriosis in the workforce. This is a

difficult area to address for those suffering with endometriosis due to the scepticism attributed to women's reproductive issues, historically being categorised as hysterical and exaggerated if they do not turn up for work due to 'period pain'. It was found that women were unsure about what to do within the workforce surrounding their disease and the difficulty it can impose on being able to do their job. So while Gilmour and colleagues (2008) emphasise how wide the impact of endometriosis is, they did not look at all aspects that contribute to QoL.

Jones, Jenkinson and Kennedy (2004) explored the impact of endometriosis on women's health-related QoL. This research used grounded theory to analyse the qualitative study done by Jones Kennedy, Barnard, Wong & Jenkinson (2001) who interviewed women about areas of health effected by endometriosis. The goal of the study by Jones et al. (2004) was to create a questionnaire that assesses the subjective health of women diagnosed with endometriosis. Jones et al. (2004) reviewed the interviews that were gathered in the earlier study and then created the Endometriosis Health Profile-30 (EHP-30) Questionnaire. Jones et al., (2004) found 86 concepts which were used to create the questionnaire in the previous study, which were then narrowed down to 15 specific and descriptive categories which helped to create the five modules that overarch the concepts, and which are demonstrated in Table 1.

Table 1

Categories of Women's Experiences of Endometriosis

Categories	Descriptions
Pain	All of the women experienced pain although different types, severity and duration

Table 1 (continued)

Physical appearance	Being sick and in pain a lot of the time meant the women felt that their physical appearance was affected negatively and that they could not put in effort to wear nice clothes etc. that they usually would
Role Performance	The endometriosis affected women's ability to fulfil their roles in society and in the home
Physical Functioning	Their mobility and ability to perform tasks was severely diminished
Social Functioning	An inability to attend social outings due to pain levels and discomfort
Control and Powerlessness	Feels that their endometriosis controls their lives and was unpredictable/uncontrollable
Emotional Wellbeing	The women had low mood or felt that they could not cope
Intercourse	Uncomfortable and painful sexual experiences
Energy and Vitality	Tiredness and fatigue
Infertility	Felt inadequate as women due to their struggle with conceiving
Employment	Had to take time off work due to being unwell or struggled to cope whilst at work

Table 1 (continued)

Daughters and Endometriosis	Concerned that their daughters may develop endometriosis
Medical Profession	Bad experiences with disbelieving doctors and poor knowledge/treatment
Treatment	Doctors just prescribed painkillers and would not help with the areas of health they wanted help with
Social Isolation	People's disbelief led women to isolate themselves as they felt they could not speak to anyone about their endometriosis

Since the creation of the EHP-30 it has been validated numerous times including in Australia (Moradi, Parker, Sneddon, Lopez & Ellwood, 2019). Pokrzywinsk et al. (2020) investigated the responsiveness of the EHP-30 scale and found that the scale was responsive in women with moderate to serve endometriosis. It is of note that the information that the women provided in this study is not typically mentioned with or associated with the disease in any other literature (Jones et al., 2004). This included feeling anxious about passing the disease on to their daughters, negative self-image, feelings of powerlessness, an inability to perform social roles or sexual intercourse, and negative feelings towards the disease as having ruined their lives (Jones et al., 2004). The creation of a questionnaire such as this reflects the growing recognition and knowledge of endometriosis and the extent that it impacts on women's lives, but it

ignores how the impacts change over time and requires the women to choose numbers rather than provide their experiences and understanding of their lived worlds.

Marinho et al. (2018) conducted a review looking at (QoL) with endometriosis. Nine different QoL measures were used including the EHP-30 but interestingly this disease specific measure was only used in 5 of the 24 articles reviewed. What this review did highlight however is that QoL for women with endometriosis was significantly lower than controls in the areas of physical functioning, roles, pain, social functioning, and mental health. Roomaney and Kagee (2016) in a qualitative study of QoL also found that pain and physical functioning impacted on all areas of life for women with endometriosis. Health related QoL for women with endometriosis has also been considered in research with findings suggesting that as the number of symptoms and severity increases, health related QoL decreases (Soliman et al., 2017). There are issues with the review by Marinho and colleagues (2018) as the measures of QoL were not consistent across studies and the studies came from 13 different countries with different medical systems. In addition, the effectiveness of the EHP-30 in measuring impact on life was not determined. But what these studies do illustrate is that women living with endometriosis face many issues which impact on perceived QoL and that having a disease specific measure may be of some use.

In contrast to other studies which have used individual interviews, Moradi, Parker, Sneddon, Lopez and Ellwood (2014) explored the impact of endometriosis on women's lives via focus groups. These focus groups consisted of 35 Australian women who were recruited from a public teaching hospital and a centre dedicated to endometriosis. These groups were divided by age: 16-24 years old, 25-34 years old, 35 years and older, as it was believed that this would allow for optimum cooperation and interaction. Two overall themes were found, theme one being "experiences of living

with endometriosis" and theme two, "the impact of endometriosis on women's lives" (Moradi et al., 2014, p.4). Moradi et al. (2014) found 14 categories within these two main themes. Within theme one there were; symptoms, delayed diagnosis, treatment, experience with health professionals, and a lack of information. Within theme two there were; physical, psychological and marital/sexual impact, impact on social life, education and employment, financial impact, impact on opportunities and on lifestyle. These categories show similarities and differences to those by Jones et al. (2004) as shown in Table 1. A key difference is that Moradi et al. (2014) divided the categories up into two main themes. Jones et al.'s (2004) article distinctly highlighted the key symptom of pain, whereas Moradi et al. (2014) created a category that incorporated all of the symptoms that were discussed. These two articles do however share similarities in some of the categories highlighting that the impact of endometriosis is felt in physical functioning, social functioning and isolation, emotional wellbeing, intimate/marital and sexual relationships, employment, treatment, and experiences with medical professionals.

Moradi et al. (2014) suggests the impact on QoL is worse for younger women. Lovkvist, Boström, Edlund, and Olovsson (2016) also found this in a study of Swedish women where women over the age of 40 had a higher QoL than younger participants. Although there were other studies on adolescent girls with endometriosis, these were mostly literature reviews or informative pieces rather than qualitative studies where the adolescent girls' experiences were prioritised, and there were also little to no comparative studies about adolescent girls' subjective experiences compared with women who suffer from the condition. Moradi et al. (2014) was able to delve into the effects of endometriosis on all aspects of life and how this effects women psychologically, especially regarding pain. This study describes females feeling un-

informed and alone as others do not understand their condition, and they therefore turn to support groups which are most accessible on social media (Moradi et al., 2014). Lovkvist et al., (2016) also found that coping strategies varied in different age groups but they did not discuss social media use as a support.

This section highlights the similar experiences that women living with endometriosis have. The common themes revolved around management, impact on life and pain. Pain is the main symptom of endometriosis and typically the most debilitating and often women had to stop or interrupt their lives to wait it out (Jones et al., 2004). Endometriosis is a secret disease, one that is not well understood in the medical profession, among men or even other women. This means women hide their symptoms, keep their disease a secret and often do not discuss their symptoms and experiences with others due to a lack of understanding (Gilmour et al., 2008). There are many aspects of women's lives that slowed down or came to a complete halt because of their endometriosis symptoms, such as careers, education, and social life, and women reported feeling like they can no longer live life the way that they would like to. Some women viewed their diagnosis as a doorway to a better self, where they actively searched for self-management strategies to help improve their symptoms (Gilmour et al., 2008). Support groups was another common theme found across the studies as women experience social isolation when they have endometriosis. Jones et al. (2004) found women are isolated due to an inability to be fully open with their friends and loved ones because of barriers such as lack of understanding and judgement. Women therefore use support groups to combat the isolation and seek self-management ideas. Moradi et al. (2014) and Huntington and Gilmour (2004) described how support groups provide the women a place to be accepted and understood so they do not feel alone in their endometriosis journey. Another common theme was about women's concept of

their physical appearance and elements of self-esteem and self-worth (e.g. Mortimer, 2002). Lastly, mood was a significant theme across the studies and the women in these studies reported frequently experiencing bouts of low mood. In addition to this, women experience frequent mood swings indicating mood is also impacting on their ability to function (Mortimer, 2002). All in all, these studies show the considerable level of impact endometriosis has on women's lives. It is evident that there are physical, mental and emotional, and life impacts from this debilitating disease. The present study wanted to build on this research gathering personal opinions and experiences of women in NZ with endometriosis.

Food and self-management

The research to date has emphasised how individualised the symptoms and management of this condition is, however, there has not been a lot of information on how food and diet is or could be used as a management strategy to help control endometriosis symptoms. There is a slowly increasing trend in articles that reference food and diet as being associated with endometriosis either as a way to manage symptoms or as a potential risk factor. Mvondo et al. (2019) links high consumption of soy products in children to an increased development of endometriosis in Asian women, and Nodler et al. (2019) links increased dairy consumption during adolescence to a decreased risk of developing endometriosis. There are foods that may exacerbate endometriosis symptoms which have been identified on the Endometriosis NZ (2019d) website. These include the FODMAP diet along with foods that are made up of animal fats, spicy food, coffee, alcohol and foods high in preservatives. However, there is not one diet that is effective for all women with endometriosis. Rowe and colleagues (2019) found this in research that explored women, health professionals and caregivers views of endometriosis. Interestingly the women with endometriosis discussed diet changes as

a potential way to resist the use of the contraceptive pill, but the health professionals endorsed medications and were reluctant to try alternative self-management strategies without sufficient evidence to support its efficacy. This study did emphasise the importance of working collaboratively in treatment as there is currently no standard diet that works for all women or other strategy that does not involve extensive money, time and effort (Rowe et al., 2019).

A review by Soave et al. (2018) also found the connection between food and endometriosis to be complex. The review highlighted that women's food choices and diet could be a potential causal factor to the development of endometriosis but there were inconsistencies across the articles reviewed. Soave and colleagues also reviewed the studies in an attempt to discuss the reactions of women to specific food items and groups in terms of the stage of endometriosis that they had. There was some indication that endometriosis could be effected by foods such as red meat, green vegetables and fruits but the variety of studies that they viewed were contradictory on these matters. They also found a lack of significant connection between endometriosis, coffee, fibres and cereal, olive oil and monosaturated fats. It should be noted that Soave and colleagues (2018) were interested in the inflammatory causes of certain foods and symptoms rather than women's experiences and what they have trialled.

Saguyod, Kelley, Velarde and Simmen (2018) also conducted a review on diet and endometriosis and how they are related due to their inflammatory response. They found foods that which are anti-inflammatory can reduce the progression of endometriosis and help to manage the associated pain. Some of the food groups discussed included fish oils, green vegetables, fruit and dairy products. There was also a positive correlation between the gluten-free diet and a reduction in the pain that women experienced. There was also the mention that the "period and duration of dietary

exposure/consumption" (p. 6) should be considered, as this appeared to have a relationship with the age and severity of endometriosis that the women had (Saguyod et al., 2018). However, this research did not talk with women or discuss the social role food plays in society, nor did they consider different points in time such as diagnosis and the management of the long-term condition.

A recent study by Sweeney et al. (2019) discussed food in relation to inflammation with a chronic illness called inflammatory bowel disease (IBD). It should be noted that IBD is distinct from IBS which is a syndrome that details a group of gastrointestinal symptoms with no known cause (Chron's & Colitis Foundation, 2019). IBD however is a disease which causes damage to the walls of the intestines due to its severe inflammation (Chron's & Colitis Foundation, 2019) and, like endometriosis, is known for its severe chronic pelvic pain and gastrointestinal issues (Sweeney et al., 2019). A key finding of this study was that all-consuming pain and the unpredictable nature of the symptoms meant that psychological issues such as anxiety were pervasive due to the feeling of not being in control of their body and not being able to control their symptoms. This study found all participants had implemented diets and these did help with their flare-ups. Specific foods were a large cause behind why their symptoms were sometimes exacerbated. This meant that leading a healthy lifestyle and making food choices was a management approach favoured by those in the study (Sweeny et al., 2019). This indicates that as with the study by Saguyod et al. (2018), diet and food choices can result in an inflammatory response in the body, and as both endometriosis and IBD are inflammatory diseases this could explain increases and decreases in flare-ups depending on food consumption.

Most of the research in the field of endometriosis tends to neglect the role of food and diet in managing endometriosis. There are some reviews and quantitative

studies that indicate a relationship between endometriosis and food, but no substantial in-depth research about the personal experience in relation to this. This is the gap that this research will address as there is a need to discover women's journey of endometriosis and how utilising food as a management tool could affect how they live with the disease.

My Research

This research primarily focuses on women's journeys and experiences in living with endometriosis, and how management through food/diet may be used to improve their lives. As such the research questions are "How do women live with the symptoms of endometriosis and how does this impact them?" and "How does food/diet effect the symptoms of endometriosis in women and consequently their lives?". This research will therefore use semi-structured interviews to discuss with the women what it is like to live with endometriosis, how it impacts their lives, what it means to them, and how they manage their symptoms, in particular with the use of food choices and diet.

As Huntington and Gilmour (2005) mention in their research, management of endometriosis and its symptoms through the medical profession is poor. There is a large focus on medication and medical procedures, with little discussion of self-management through lifestyle changes. Both studies by Huntington and Gilmour (2005) and Gilmour et al. (2008) frame their studies from a feminist perspective, which provides great insight into women living with endometriosis and highlights these issues surrounding women and the medical profession. This is another key aspect to this study to ensure that the women are heard, valued and the biomedical paternalistic system can be challenged. It is important that this research looks beyond the medical strategies to the lived worlds of women, where they integrate health information such as diet in ways that are unique to them.

The aim of this research is therefore to discover how women live with and experience endometriosis and its symptoms, and how food-related and dietary changes they have made have impacted on this either positively or negatively. The hope is to highlight the importance of alternative management methods to ease symptoms of endometriosis, which could be as simple as making healthier choices in terms of food and cutting out those individual foods which specifically exacerbate symptoms in each woman. Making healthier food choices and being sensible as to which foods are irritants to them is important for some people, however it could be life changing for those women with endometriosis, hence the desire for this research to investigate this topic.

Chapter Three

Methods Chapter

Endometriosis is a deeply personal and important topic to me, and to other women as well. It is a condition that presents so individualised that it needs to be treated with sensitivity to understand the many interweaving facets. This research was conducted to better understand the complex nature of endometriosis and women's experiences with the disease. This chapter outlines the method of my research and how I conducted interviews with women who have endometriosis. The research explored women's experiences with endometriosis throughout their lifetime both before and after diagnosis, and how they attempted to manage this disease through food and other alternative methods. Qualitative semi-structured interviews were chosen as the means of data collection to ensure that I could create a connection with the participants and gain a rich and deep level of understanding about their lived experiences with endometriosis. Enhancing this was the self-disclosure made by myself to the participants about my own struggle with endometriosis in the hopes of creating an equal and trusting relationship. This was important as the research involved two interviews, in addition to the completion of a food diary. This chapter will discuss my theoretical perspective and research orientation, the recruitment, procedure and interview processes, and the analytical approach I took when interpreting the transcripts.

Theoretical Perspective

This research was conducted qualitatively because I wanted to allow the participants to share their thoughts and lived experiences, whilst having the freedom to discuss aspects of the subject matter that they viewed as being relevant and important (Horton, Macve & Struyven, 2004). This is because there is a lack of research privileging the experiences of women whilst treating them as experts in their own body.

Social constructionism is the lens through which this research was conducted as people's knowledge is seen as being constructed through their experiences and social interactions (Burr, 2015). Social constructionism is an epistemological viewpoint which explains that knowledge and understanding is created through social interaction and discourse between people (Andrews, 2012). Therefore, social constructionism states that knowledge cannot be separate from the individual, where no one can be completely objective (Burr, 2015). It is evident from the introduction that women's bodies, particularly reproductive bodies, are most often understood through a biomedical lens and the power is given to the medical professionals as experts rather than the women themselves. By framing the research using social constructionism I can privilege the women's lived experiences, their voice and their journey with endometriosis, whilst having a critical stance of the dominant ways that medicine understands and treats women with endometriosis (Burr, 2015). In addition, from a social constructionist perspective it is imperative to consider history, politics, culture and how these have influenced our understanding of the world (Gergen, 1973). As such, this research aimed to examine women's knowledge and experience with endometriosis and explore how society has impacted on these individuals. This was able to occur as the participants were viewed as being as equally knowledgeable as the researcher (Burr, 2015), where they were treated as an expert in living with endometriosis and where the knowledge was co-constructed (Clarke & Braun, 2018).

In addition, this research is framed from a feminist perspective. Feminist scholars consistently argue that women's experiences with menstruation and reproductive health are understood and perceived from a sociocultural context and are profoundly gendered (e.g., Johnston-Robledo & Stubbs, 2012; Mondragon & Txertudi, 2019). This is important as it is abundantly clear that there is still a lot of shame and

stigma surrounding the menstrual cycle, female health and gynaecological conditions (Ussher, 2006). It is important to consider the broader sociocultural context as women and young girls' attitudes and experiences are located within their social context (Johnston-Robledo & Stubbs, 2012). For example, stigma associated with menstruation can be partly blamed on a lack of awareness and knowledge taught to children, where young girls are often not educated on periods before menarche and so can often associate it with trauma, fear and embarrassment (Ussher, 2006). Young boys are also not educated to be more aware and accepting of girls getting their periods which can lead to ostracization and bullying, reinforcing the notion that women have lower status in society (Johnston-Robledo & Stubbs, 2012).

This research uses a critical feminist framework assumption outlined by Lafrance and Wigginton (2019). Research questions are not neutral but imbued in power, where even the language the questions are framed in is important and requires constant reflection. It is important in this tradition to be reflexive throughout the entire research process. This personal reflexivity sits alongside "functional reflexivity" (p. 8) which is the premise and worth of the research itself, both of which are important when analysing the data. Lastly, critical feminist research highlights and challenges the dominant and problematic discourses that are prevalent. It is important for questions to be asked surrounding the methodological approach to ensure that the principles promoted by feminist research—vitality, diversity and innovation—are adhered to (Lafrance & Wigginton, 2019). As such, in this research I ensured I was reflexive, asking what approach I took and why. My personal experiences with endometriosis assisted me by providing me with a commonality with participants and allowing me to have some insight into what they experienced. The goal was to allow the women a voice and to promote their stories (Lafrance & Wigginton, 2019).

A key reason as to why this research is conducted from a feminist perspective is that endometriosis typically starts from a girl's menarche and their symptoms are therefore often blamed on their period. How women perceive menstruation and themselves throughout this stage of their lives, reflects women's ideas about being a female and what this means (Johnston-Robledo & Stubbs, 2012). Females experiences of menstruation are surrounded by stigma and most women are hesitant to openly discuss their periods (Strange, 2000). Johnston-Robledo and Chrisler (2011) discuss the social stigma surrounding menstruation in women. Menstruation is seen as a curse, unpleasant and disgusting and as such is something that should not be discussed in public. Many cultures have negative perceptions of menstruation as being unsanitary and abhorrent, which is then transferred to ideas about women, as menstruation is an indicator of being female. In Māori culture for instance, when a woman is menstruating her body is viewed as being tapu (sacred and forbidden) and as such women are prevented from participating in Māori customs and visiting sites such as an urupa (cemetery) as they will contaminate a site that helps provide sustenance and balance to Te Ao Māori (Māori worldview) (Wikitoria, 2004).

Johnston-Robledo and Chrisler (2011) explain that stigma surrounding women's health means that women often hide any indication that they are menstruating, which in turn reinforces societies stigmatising attitude towards them. The creation of feminine hygiene products and how they are advertised contributes to societal attitudes as they are described as being miniscule, easily concealed, not visible to others through clothing, and that they conceal any odours. This is what is promoted as being normal etiquette in experiencing menstruation and contributes to women being self-conscious, cautious and attentive, to hide the fact that they are menstruating. The work required to monitor themselves to ensure they display a façade of normalcy is extensive, all in an

effort to present themselves both physically and verbally in a way that detracts from the idea that they could be menstruating (Johnston-Robledo & Chrisler, 2011). This narrative also ignores the costs associated with periods both in terms of monetary cost and assumes that all women have access to period products and accurate health knowledge. Oxley (1998) advocates for the idea that women need to take control of their experiences of menstruation and how they feel about it and themselves at every point in their cycle, they must resist culture's negative perceptions of their menstruating body and take charge of the discourse surrounding menstruation and women's health. In agreement with Oxley (1998) this study gives women a platform to discuss women's health issues and endometriosis, to spread awareness and knowledge in an attempt to reduce society's stigma and negative attitudes.

It is also clear that the medical profession is highly masculinised and is taught in such a way as to prioritise male's health rather than female's health (Govender & Penn-Kekana, 2008). This is supplemented by gender-stereotyping, where females are typically less likely to be diagnosed with a variety of illnesses including tuberculosis and are also exposed to less intensive treatments than their male counterparts for illnesses such as heart disease (Govender & Penn-Kekana, 2008). Findlay (1992) explained the attention of the medical profession for women focuses on controlling reproductive functioning and menstruation in order to prioritise childbearing. The goal of being pregnant and becoming a mother was classified as normal which is highly problematic for women who cannot have children, who chose not to have children, young girls or trans-binary women. In addition to this, medical interactions are inherently unbalanced in terms of power. For a woman presenting with pelvic pain they are at a disadvantage in terms of medical knowledge, often they are young and need an

advocate present, and the medical professional is taught that period pain is normal (Findlay, 1992).

The powerful position of medical professionals means that women are often misdiagnosed or not helped at all due to the gender discrimination that is prominent in the medical field, and the lack of knowledge and stigma surrounding women's health (Govender & Penn-Kekana, 2008). This all attributes to the astounding average diagnosis delay of eight years (Endometriosis New Zealand, 2019a). Therefore, the feminist perspective used in this research will highlight these points and advocate for gender equality for patients in the medical field, and the need to educate the medical professionals, both old and new, about women's health and illness.

Participants

A sample of eight female participants between the ages of eighteen and forty-six were recruited for this study. There were inclusion criteria that participants had to meet in order to participate. Women younger than eighteen were deemed less likely to have received a diagnosis as the average time is eight years from first period. The criteria specified women who were living in NZ and who had a diagnosis of endometriosis through the use of a laparoscopy for a minimum of three years could participate. They must also have made changes to their food choices or adapted to diets in order to participate. The reason for this set of criteria was to protect the participants from possible harm, whereby it was thought that women who had been living with endometriosis for longer would be more comfortable discussing aspects of the disease than women who were still adjusting to their diagnosis. The participants being over the age of eighteen meant that they could understand what was expected and provide informed consent without a guardian. Further, the criteria would allow for more depth of data, where some of the data being collected would be about food choices and

alternative medicines to manage the disease. As such, those who had the disease for longer were believed to have been more likely to have tried a range of management methods distinct from medicinal ones. Lastly, having the participants reside in NZ was for ease of access to participants for interviews in person and via the phone or skype (without additional costs, time differences or language barriers). These criteria were outlined in the information sheet (Appendix A) and advertisement (Appendix B) for the participants to see prior to signing the consent form (Appendix C).

Table 2

Participants Self-identified Demographic Information

Participant ID	Age	Ethnicity	Age of Surgical Diagnosis	Age of first symptom
Sally	18	NZ European	17	13
Tania	46	NZ European	21	10
Chloe	22	British	20	12
Sonia	36	NZ European	35	13
Megan	23	NZ European	18	13
Susan	40	Kiwi/White	20 and then 38	12
Grace	21	English	17	13
Rebekah	25	Kiwi/British	22	19

The demographic information that was collected from participants is provided in Table 2. As is demonstrated, I had to be more flexible about the criteria that the women had to have been diagnosed for three years. This was because I ran into the challenge of many women having lived with endometriosis since a very young age but having only been recently diagnosed. I found they still had a great depth of knowledge around the

disease and their experiences, and so I allowed women to participate who had received their endometriosis diagnosis less than three years ago. This criterion was originally in place as a part of procedural ethics (Guillemin & Gillam, 2004), however, it turned out to not be complicated in finding participants that could fulfil the requirements for this study. This could also be because endometriosis is not well understood, there is minimal research on the subject and it is only really being discussed now (Mehedintu, Plotogea, Ionescu & Antonovici, 2014). I have compiled a brief description of each of the participants experiences to acknowledge each individual journey (Appendix D).

Procedures

Recruitment. Participants were recruited via the social media platform, Facebook. The administrators of two Facebook groups were contacted via private message to ask if an advertisement could be shared on their Facebook page, with the intention of recruiting their followers. The Facebook pages chosen were centred around endometriosis and supporting women who live with and know others with this disease. Anyone can request to be part of these groups and so the population of the groups are diverse, but their followers are typically women, and would either be living with endometriosis or know someone who is living with it. The administrators were given information on the study and were asked if they or I could share the advertisement on their page, which included a brief summary of the study and my contact information for prospective participants to contact me if interested. The participants were given the information sheet via email if they wished to know more about the study and they were free to ask any questions. A consent form was filled in and signed by each willing participant before each interview.

The reason for recruitment through Facebook was that it was easy to search for and access a group of people based on specific characteristics (Whitaker, Stevelink &

Fear, 2017). Facebook has a variety of people who join groups for support for particular health conditions and which are easily accessible, and so posting advertisements on this platform means that many people can view the advertisement and share it with others (Whitaker et al., 2017). It should be noted that online recruitment could exclude people from lower socioeconomic areas who may not have access to a computer or regular Wi-Fi. The visibility and sharing of the post are up to the audience, and so choosing the right audience to post to is pivotal (Whitaker et al., 2017). To address this, I used specific endometriosis support and awareness groups.

With the recruitment stage of this study there were some challenges, such as waiting on a response to the request letters from the Facebook group administrators that I contacted. This took more time than I expected, where one group took a number of days to respond and the other did not respond until after I had recruited all participants. This meant that I could not post the advertisement to one group straight away and the other not at all, causing an initial delay in participant recruitment. Another challenge faced was the process of gaining informed consent from participants. It took numerous days to receive a signed consent form. This could be attributed to being out of sight out of mind, where because recruitment was done online, participants may have forgotten about it. One week after I had not heard anything from the potential participants, I contacted them again to see if they were still interested in participating and they then proceeded to send me the required forms.

Interviews. The interviews were stated in the advertisement as being available in person if the participant lived in Auckland, on the telephone or via skype. The choice of platform and the location of the interview was up to the participants. The initial interview time and place was organised once the consent form had been signed, and the second interview was organised approximately one week after the initial interview,

which was about the participants completed food diary (Appendix E) that they were asked to fill in between the interviews.

The interviews were recorded on two platforms, one on the voice memo application on my MacBook and one on a digital voice recorder. I also tried to record the interviews on the Otter application, but this did not work. I was glad to have recorded on two platforms as a couple of times throughout the interviews one platform was not turned on properly, failed to record, or had poor sound quality. This meant I could use both platforms to accurately transcribe the interviews.

First interview. Before the first interview, once the participant had consented to participate, demographic information was collected from the participants via a demographic information sheet (Appendix F). This provided me with information such as self-identified ethnicity data, which was pivotal in conducting this study. To initiate interviews with participants in a way that made them feel comfortable it was important to consider their cultural practices or expectations prior to interviewing them, such as the correct way to greet someone and etiquette surrounding being in someone else's home. Researching and preparing to participate in cultural practices for the interviews helped me to feel more at ease and comfortable with the idea of establishing and facilitating good relationship if a participant identified as a different ethnicity to myself. However, as Table 1 shows, all the participants in this study identified as NZ European/Kiwi/British, and so I did not need to practically apply the cultural research to the interviews. However, I do see the lack of cultural diversity as a downfall to this study despite being out of my control. It would have been interesting to hear about women's experiences relating to endometriosis and food practices from outside of the 'Pākehā' (non-Māori) culture, to see if it was lived and perceived in the same way.

The first interviews lasted for approximately one hour, with only one taking significantly less time of twenty-five minutes. These interviews covered topics including the diagnosis and journey of the women's endometriosis, symptoms, and the impact of the disease on the women and their lives. These interviews were participant-led and had a conversational tone, rather than a formal, structured one. I had prepared some prompts and questions in the form of an interview schedule (Appendix G) to guide the interviews when the conversation was lacking, but otherwise the participants decided what to discuss and how long to do so (within the topic of endometriosis). Participants were all sent a document explaining where to seek help (Appendix H) if they felt distressed by the interviews.

Once the interview was complete there was some off the record conversation to wind down from the interview and to ensure that the participant was feeling good about what had just taken place. Participants were also given instructions pertaining to the food diary task in preparation for the second interview and were told they would be contacted in one week to see how they were going and to organise said interview.

Food diary. Participants were asked to fill in a food diary between the first and second interviews, which had the option of being written in a book, on the computer in a Microsoft Word document, or on the notepad application on their phones, depending on what was convenient to them. They were asked to include information about their food choices, and diets they had implemented before and after being diagnosed with endometriosis. They were instructed to describe how these food choices effected their symptoms and consequently their management of the disease and how this had impacted on their lives and emotions. The food diaries were an invaluable prompt for the second interview and to help the interviewee remember diets and other strategies they had tried.

Second interview. The second interview attempted to uncover the food choices and diet implementations of women with endometriosis, where the food diaries were used to guide the conversation. The participants were asked about their food diaries, food choices, diets, the effect these choices have made on their symptoms and how this has impacted on their lives and their functioning, which included personal, social, mental and emotional factors. This ascertained how the management of endometriosis through diet could impact on the lives and wellbeing of women who suffer with the disease.

After both interviews had been conducted, I asked the participants if they had a postal address I could have, to send them a token/koha of my gratitude to thank them for participating and sharing their experiences with me so willingly. After all interviews were done, I used the voice recordings to write transcripts of each interview. I created a key for pauses, exaggerations and so forth, so that when I went back through the transcripts, I could visualise the interview and its tone. Each transcript was then sent to each participant that indicated they would like to see their transcripts to read over, providing them with the opportunity to clarify or omit anything they had said. A transcript release form (Appendix I) was given to them to sign once they had read their transcripts, where their signatures meant that they agreed to release their interview transcripts and the information that they had provided into my care for the study. No participants in this study made any changes to the transcripts which were then used for data analysis.

Ethical Issues

Human Ethics Application NOR 19/35 was approved by Massey University's Northern Ethics Committee. Initially I believed this study to be low ethical risk, as the topic was not highly sensitive, traumatising or controversial. However, due to the advice

that arose from a peer review of the low-risk application, I decided to submit a full ethics application.

The key ethical concern was the potential of causing embarrassment or discomfort to the participants. This is because some topics discussed in the interviews were personal and sensitive in nature, including the endometriosis symptoms of painful periods, sexual intercourse and bowel issues. This potential for discomfort was alleviated by the fact that participants were having their interviews with myself—someone who is female and lives with an endometriosis diagnosis—and so I was able to understand and empathise about their situation and experiences. This was highlighted in the interviews where participants would relate and refer to me as having been through the same experience, through comments such as: *"you know what it's like", "cos you know the pain", "obviously you know that".* In addition to this, many of the participants had become accustomed to discussing living with endometriosis and the symptoms and difficulties surrounding the diagnosis. This was demonstrated in the interviews with their openness and willingness to talk, bringing personal topics up themselves without any prompting. Some women discussed their desire to talk about it: *"it [endo] has made me a way more open person", "I do also like to talk about it [endo] a lot", "I like to talk about it [endo] because it helps other people".* I also initially had the requirement that participants should have been living with the diagnosis for a minimum of three years, indicating that they have spoken about their issues with many people over this period of time including friends, family, medical professionals and so forth. However, as previously mentioned it was found that a lot of women had a more recent diagnosis and so did not quite meet the three-year diagnosis criteria. I therefore deleted this criterion as all women were at a point of acceptance with their disease and could all talk

about it comfortably and with an abundance of detail, having lived with it for years before diagnosis.

The Te Ara Tika Guidelines for Māori research ethics was used to inform the ethical application of this study. Aligning with the Massey University code of ethics, it was important to consider tangata whenua and the Treaty of Waitangi principles to promote equality and partnership. Things that were considered included whakapapa and as such the quality of relationship between interviewer and participant, tika and the alignment of the research and Māori goals, manaakitanga where cultural safety is essential, and mana which refers to power, autonomy and justice (The Pūtaiora Writing Group, n.d.). I had two cultural consultations with the cultural liaison at Massey University, with in-depth discussion about how I could accommodate cultures within my interviews, especially with the Māori culture and upholding the Treaty of Waitangi. I formulated these ideas into a document (Appendix J). This included practices such as respecting the participant's whare in taking off my shoes and bringing kai, developing whakawhanaungatanga, initiating pepeha and karakia, and ensuring that their results would be presented in a non-deficit-based manner. However, the participants in this research all identified as NZ European/Kiwi/White and so I did not need to practically apply specific Māori (or other cultural groups) customs to the interviews.

Reflexivity

Reflexivity is a method of quality control used in qualitative research to ensure the researcher's experiences, beliefs and values do not affect the interpretation and overall outcome of the study (Berger, 2013). Researchers need to be able to separate their thoughts, experiences and position on a topic from themselves, because of the nature of qualitative research, where the researcher immerses themselves within the topic and literature, collecting their own data and then interpreting it (Berger, 2013). In

instances where researchers have a close personal connection or beliefs about the topic they are investigating, reflection is extremely important. This is because researchers who have experienced what they are investigating (such as living with endometriosis) have their own truth, knowledge and memories about the topic (Alvesson & Sköldberg, 2018). The researcher should be able to acknowledge and then distinguish between their knowledge and the information they acquire, to limit preconceived ideas brought into the study by the researchers themselves, ensuring all information is derived from the research itself (Alvesson & Sköldberg, 2018).

Reflexivity provides transparency between the researcher and participant within the research itself, where reflection could occur on where ideas came from and if they are valid, and with the audience of the research who will recognise the honesty and expertise of the researcher (Alvesson & Sköldberg, 2018). Self-disclosing pivotal and relevant information creates an alliance with the participants, producing a more equal relationship between themselves and the interviewer (Zur, Williams, Lehavot & Knapp, 2009). This can help the participant feel comfortable discussing personal aspects of their lives as they may feel it more likely the interviewer will understand their stories (Zur et al., 2009). As long as the information shared does not affect the participant negatively and has a purpose, then self-disclosing and reflecting on aspects of the interviewer's life can be helpful (Zur et al., 2009).

This study is relatable to me as I was diagnosed with endometriosis five years ago, when I was nineteen years old, after years of searching for a diagnosis. I experienced difficulties with doctors and specialists being disbelieving of myself and the symptoms I was experiencing, repeatedly telling me that nothing was wrong with me. After years of suffering with the symptoms and other's judgements, I convinced a gynaecologist to perform diagnostic surgery where endometriosis *was* found, but this

was not the end of my journey. There have since been countless appointments made, endless forms of hormonal contraceptives, injections and pills trialled, and I now currently rely on painkillers, anti-inflammatories and opiates to get through flare-ups. I find support groups on Facebook to be highly valuable, as are other websites that provide alternative information on managing endometriosis from women who live with the condition. This is why I wish to investigate women's experiences of living with endometriosis and how this is affected by food choices, as diet is consistently brought up on these sites.

The reason I am disclosing this information is so that the audience is aware that I live with endometriosis and that I was capable of being understanding and empathetic towards the women I interviewed. In turn, I hope they felt more comfortable talking to me about such a personal topic. It was my intention to guide and support them whilst they shared their stories, staying accountable with my knowledge whilst keeping it separate so as not to overpower their stories. I wanted the women to have a voice and be the expert on their own lives.

Throughout this research process, especially with the analysis, I found I was constantly reflecting on my journey and comparing what I went through with what the women were telling me they had experienced. Many experiences were similar, however, I found that much of what I had heard from these women were horrifying compared to what I have experienced thus far. I felt a deep sense of sadness for them whilst also feeling relieved and grateful that I did not endure what they did. I felt a strong sense of connectedness with these women, particularly with how they were continuing to endure the disease and try their best to live their lives to the fullest, which is what I try to do. They showed a rawness and realness which allowed me to have great insight into their lives and experiences, that I was not entirely expecting but for which I am grateful. This

allowed me to thoroughly understand what they were trying to convey, and I hope I reflected this well in this research.

Speaking with participants about their endometriosis and how they have used diet as a management method has inspired me to take my health more seriously, where I have decided to research management avenues that would be beneficial to myself. Conducting this research further ignited my passion for spreading of awareness of endometriosis and the profound impact it has on women's lives. I feel privileged to be in the position that I can conduct future research in this area which so deeply affects myself and others, and I am inspired to do so.

Data Analysis

Thematic analysis (TA) is the chosen data analysis method for this research as it is used to seek out patterns across a qualitative dataset in order to answer research questions. Braun and Clarke (2006) describe that these patterns are found through "a method for identifying, analysing and reporting patterns (themes) within data" (p. 81), while describing the collected data in detail. Clarke and Braun (2018) describe that a theme is more than a summary of the participant responses but rather a "central organising concept" (p.108) that underlies and unites the observations. Themes should actively be created to look for shared meanings, contrasts and differing views. Rich TA should move from description into interpretation and tell a story answering the critical aspect of this research (Clarke & Braun, 2018). Using TA means that we should acknowledge our theoretical perspective and be clear about theory (Braun & Clarke, 2006). The method itself can be approached in several different ways. In this thesis the analysis was approached in an inductive manner, meaning that the themes generated were led by the data. TA was chosen as it can be flexible in this way (Braun & Clarke, 2006). What should be made clear is that the assumptions for this TA are consistent

with what Clarke and Braun (2018) call reflexive TA as this fit with the social constructionist and critical feminist psychology epistemology and theoretical perspective of this research. Braun and Clarke have developed quality criteria which includes being highly reflective, making the assumptions of the research very clear, and highlighting how themes are central organising concepts that have been fully interpreted (Braun et al., 2019). Reflexive TA is a process that informs the methodological framework, and so was important for this work to explore women's experiences and knowledge without any bias or influence, to gain a better understanding of the women's experiences living with endometriosis and the impact of food on this (Braun & Clarke, 2006).

Braun and Clarke (2006) describe six steps to thematic analysis: 1. Involves transcribing the verbal data, familiarising yourself with this data by reading and re-reading the transcripts, and highlighting and writing down key ideas that stand out. 2. The first round of coding starts in this step, where any interesting ideas that the data presents are coded and overarching themes in the data are considered and noted down. 3. Once coding is finished, these codes are then grouped under different overarching themes that they relate to. 4. The relationships between codes, themes and sub-themes are evaluated, and they either need to be strong/relevant or they should be changed or discarded. Strong themes will have plenty of data/codes which support them, and the codes within each theme should also form a coherent pattern. 5. This step involves further refining the themes, ensuring they are not too diverse or restricted and ensuring there is no overlap between each one. It is also essential to know how each theme fits into the overall story of the data and the research questions; you should know what you plan to write about in the data analysis section in regard to these themes. 6. Producing the data analysis section for the study where the themes identified should be discussed

between and within each transcript, and where each theme should be interpreted and explained beyond the data in relation to the overarching questions and topics the research is intending to cover (Braun & Clarke, 2006).

What this meant in practice for me was the following: 1. Included listening through the recorded interviews and writing them down in full, which was followed by 2. where I listened to the recordings again to ensure that what I transcribed was accurate and so that I could include a key for any verbal expressions or emphases that the participant may have had. 3. Included reading over the transcripts and making notes on the ideas and codes that appeared and highlighting any interesting quotes that were seen. 4. Involved deciding on the overarching themes of the study based on what the codes seemed to be communicating, and as such 5. involved grouping those codes under each theme based on what they represented. 6. I wrote down each theme and the corresponding codes and outlined the description of each, provided useful quotations from participants and provided a reflection on the overall theme about my personal lived experience. This is important because each woman in this study told a story to me whereby I gauge their meaning and argue the importance of their message, and as such it is important to recognise that my interpretation of the women's stories could be influenced by my personal experience and beliefs, and so acknowledging this helped me stay accountable (Braun et al., 2019). Conducting the analysis this way meant I was able to eliminate any overlapping themes and themes which I thought were more prominent than they actually were. It also meant that I was ensuring I knew what each theme meant and how I could discuss it when I got to the write up at stage seven. 7. The write-up consisted of the findings section where I elaborated on the writing I conducted for stage six, and also the discussion section where I further discussed and analysed the

findings, presenting and highlighting those themes and sub-themes which were the most prominent, interesting and useful to the world of endometriosis.

Chapter Four

Findings

This chapter will outline the six themes. Quotations used throughout this chapter with sections underlined show the participants emphasis, not my own.

Impact on Life

This theme captures that endometriosis is a disease which dramatically effects and disrupts all aspects of women's lives. Their lives are adapted and worked around their illness including their education, jobs, careers, and daily lives. The women think and plan around their pain, periods and their energy levels, as these can be exacerbated at certain periods in the month. This in turn impacts on their willingness and ability to leave the house. This theme explores how endometriosis impacts intimate relationships and friendships and the strategies women use to balance health with these relationships. In addition, the financial burden of this disease is discussed, highlighting the inequalities facing women who do not have health insurance or access to paid medical care. Endometriosis, in most respects consumes women's lives, making managing their symptoms a priority in order to reduce the effect it has.

Debilitation and absence

The women in this study described how debilitating their endometriosis symptoms can be. The pain is so bad they are often unable to move and cannot perform what is required of them in their everyday lives. Living with this pain was at times traumatic for the women, often not being able to perform simple tasks such as driving or exercising due to the severity of their pain, where there was nothing they could do to help their situation except stop, cry and live through the agony until the flare-up passed.

> *"I can just remember it being the most debilitating pain I've ever experienced in my life…I can remember being in my bedroom and crying on the floor and Mum not really knowing what to do" (Sally).*

"now I have a disability park and I can't really exercise, cos I can barely walk" (Chloe).

This debilitating and emotional pain lead the women to try and manage their pain with different painful stimuli in an effort to distract themselves from their endometriosis symptoms. Grace described the crippling pain and nausea associated with her endometriosis, and how the burning heat from a hot water bottle directly pressed on her skin still felt better than feeling the endometriosis pain solely on its own: *"it was more like the bloating and the feeling sick and just the constant stabbing, and the fact that like having a hot water bottle held on you, and it literally burning your skin… Was easier than dealing with your pain at what it was".* In addition, Susan described that as a teenager she would *"bang my head against the wall literally trying to inflict pain somewhere else on my body cos I couldn't focus or cope with the pain elsewhere"* and where currently "*I tense my toes… And kind of tense the rest of my body and like I control tense my arms and fingers and hands, and dig my fingernails into my arms or legs or something".* Apart from medication, heat and painful stimuli was one of the only things that the women mentioned could help ease the symptoms slightly during a flare-up.

While the severe pain made the women feel powerless and helpless, it also consumed all of their energy. Even on the days the women were not in severe pain, the constant worry, anticipation of flare-ups or tiredness from dealing with previous flare-ups meant everyday activities were difficult, including going to the supermarket, cooking or cleaning.

"I think it's just this constant battle, and it's so exhausting because I get sick so much easier than everybody else, I feel like I just have to do life at such a slower pace" (Grace).

"I'm so tired. Like I get so fatigued, so at about 3-4 o'clock I'm just wrecked… I just can't actually get out to do anything" (Rebekah).

Sexual and romantic relations

The women in this study described the limited or absence of sexual relations and how this impacted on their relationships. The predominant feeling the women expressed was guilt—guilt because they did not want to have sex due to the pain that it caused, but wanting to give their partners what they perceived as something that he needs/deserves. The women reported that they believed their partners also felt guilty for causing the women pain during sex. The women thought their partners would not initiate sex with them in order to protect them, which caused them further guilt and reduced spontaneity. This was portrayed by Sonia where *"I feel quite guilty [about not having sex], I mean my husband is incredibly understanding… I guess he sort of takes the stance that he just wants me to feel better and he doesn't want to do anything that's gonna hurt me… which is amazing but at the same time I feel really guilty for not feeling well enough".* The women described having to mentally and physically prepare themselves to have sex, taking away the simplicity of sexual relations. These preparations could be the taking of pain medications prior and talking oneself into having sex by telling themselves it would be worth it afterward for the sake of the relationship. Susan described her intimate relationship with her partner, *"So I just don't [have sex]… Unless I've already got quite a few drugs on board and I can manage it and I'm in a good headspace to manage it… he's very cautious about initiating sex, it's not a spontaneous scenario generally… he doesn't want to hurt me… So it's more I initiate it now because I think I've got a handle on it or because I know that he… needs it… More as opposed to me craving it necessarily or anything else, it's more that I make a conscious decision…to go about it…clinical really" (Susan).* This also demonstrated

how the women felt that they had to sacrifice their female body, where decisions such as when to have sex were made out of feelings of guilt or obligation.

Sexual relations were seen as important in their intimate relationships so they made conscious decisions and ensured they prepared physically and mentally first. Despite preparation the women described sex as painful during and afterwards, with the chronic pain often lingering for hours. Two of the participants (Chloe and Sonia) currently do not have sex with their partners due to the pain, and all of the women had gone through periods of avoiding sex. This was more difficult at the start of a relationship. Tania says "*it did impact mine and (boyfriends) relationship… Yeah [he didn't fully understand] and also our sex life… I didn't want to, cos sometimes it would really hurt… And afterwards-who wants to be in pain for five hours afterwards… he would feel really bad for me*".

> *"I sort of take a similar approach to going to the gym, like I know that it's [sex] an important part of our relationship and I don't want to miss out on that, even though it's not particularly comfortable sometimes… I tend to sort of…suck it up and enjoy it as much as I can" (Sonia).*

The women explained that their partners always showed them care and support, and that with increased exposure and education on the topic their awareness and understanding grew. Interest in learning and educating oneself was highlighted as a crucial step to gaining that level of understanding needed to be in a strong relationship with a woman with endometriosis. The couple had to work together to work out how to cope and at times this bought couples closer together.

> *"the relationship that I have with my husband while it's not ideal that I have this stupid disease that's never going to go away, to some extent it has brought*

us closer together as its sort of this thing that we have sort of been learning about together, and he's been so supportive" (Sonia).

The impact of endometriosis is such that if partners are not supportive or understanding this often leads to turmoil and consequently the relationship ends. This was the case for Sonia where she explained *"my ex-husband was certainly not as understanding, empathetic or compassionate as my current husband… he also didn't really understand or didn't care to understand why I might not want to have sex as often as he might like".* Sonia describes being viewed as an annoyance and acting the sick person by her ex-husband, which caused embarrassment and frustration on his part. This could be exacerbated by the fact that Sonia's ex-husband was present prior to her endometriosis diagnosis, meaning that there was no explanation as to why she was experiencing these things. Sonia expressed this in her interview, *"to some extent I think, my endometriosis and the issues that I was having before I even knew I had endometriosis, possibly contributed to the break-up and the break-down of my previous relationship".*

In contrast to feeling like they should have sex with their partners, the women also expressed gratitude and luck for finding understanding partners who put up with their needs and their moods. The women admitted how difficult it must be living with them, their symptoms and associated mood swings, and expressed gratitude and admiration that their partners stay with them as well as feelings of guilt.

"And my relationship, cos its quite hard living with someone with endometriosis… for a while it kind of took over my life" (Tania).

"me being in pain all the time is really hard, like he has to do a lot of things around the house cos I am just dead most of the time…I feel really bad about that" (Chloe).

"it makes me very, very moody and temperamental, I do not have a big temper but I have thrown a few plates of food at my boyfriend" (Susan).

One of the participants, Rebekah did express her concern that her endometriosis and her behaviour may become too much for her partner and that this would cause him to leave her. *"[Concern] definitely for my relationship, I mean it doesn't matter how good your partner is, at some point they're gonna break" (Rebekah).* She worried that her partner would inevitably leave her, despite how supportive and understanding she described him as being, and how much he loves her. This could be partially due to the gendered nature of relationships, whereby it is a commonly believed stereotype that it is the women's role to care for their men and to take care of the household (Atkinson, 1987). As such the women in this study discuss anxiety and fear surrounding them not being able to participate in their feminine duties and so believe that their partners will become dissatisfied and will leave them.

Maintaining friendships

The participants described how extensively their social life has been impacted on by their endometriosis. The symptoms can be so severe and constant that the women have no energy left for anything other than the things that they must do (work, school etc.), leaving no wish to socialise with others at the end of the day. Chloe described that *"by the end of the day I'm shattered and that's the time people go out and have events and stuff, and that's the time that I don't want to be going out".* The fatigue that the women experience can therefore impact significantly on their relationships. Participants commented on losing friends and being alienated from social gatherings because of the difficulties they face surrounding upkeep of the relationship, and the fact that a lot of the time they could not attend because they were sick, leaving their friends feeling neglected. Sonia, Chloe and Grace said they had lost friends due to their endometriosis.

> *"friendship wise, I feel like I've lost friends because I don't do a lot. I mean I miss uni a lot cos I'm in pain and then I spend lots of time catching up at home so I don't actually go to lectures so I don't meet people and make friends" (Chloe).*
>
> *"if I do [make plans] in the weekend I normally end up having to cancel, and I hate cancelling but I just run out of energy and then, some of your friends aren't quite as understanding and they're like 'oh my gosh you're bailing…you're flaking' and you're just like 'get wrecked, that's so unfair'" (Grace).*

Endometriosis resulted in some of the women feeling as though their friends excluded them from certain gatherings and events and reportedly there were people who found being friends with a woman who has endometriosis as too challenging. This then left the women feeling left out and alone at home, which although was better for their physical health did not help their mental and emotional health. Susan said *"I'm not willing to give up on my social [life] you know like, it already affects everything so why would I give up more for it?".* This shows the women's desire to participate in a social environment with their friends but that *"maybe if I just don't come at all then that will be easier for everyone'" (Grace).* Some however described that their friends they have left are good friends, ones that are supportive and try their best to understand their endometriosis. Sonia explained that *"you learn who your real friends are I think, going through something like this… Yeah, that don't want to or can't [understand], or its too triggering for them for whatever reason and so they pull back".* Having people around the women who are supportive and understanding is important for the women's well-being, whether this be their partner, family or friends, as it makes living with endometriosis easier. The women found that their friends who were supportive made the extra effort to ensure that they were coping and that the socialisation at times was catered to them and their needs. They made real attempts to show the women that they

are loved, that they are there for them, believe in them and can sympathise with their plight. But like partners, friends were seen as people who still did not really understand endometriosis. As Sally says *"in terms of social life, I've been very lucky in that my friends are the most supportive people… even though, like I know they don't quite get it."* Having supportive friends makes the disease more manageable in the sense that the women have a support network, those who will check in with them and make a conscious choice to visit them and lift their spirits. Having this can make the world of difference to the women who described the difficult times that they have had and are continuing to go through.

A large part of socialising revolved around either food or alcohol, so there were many social activities which made the women feel alienated because they were on restricted diets and because alcohol may worsen symptoms. Rebekah explained that *"I don't like going out…the amount of times I've gone out to dinner and my partners had to come and pick me up early… number one it's not cool, number two like I just want to enjoy my meal that I just paid $30 for you know?"*. Rebekah mentioned here the unfairness and the upset caused by having to leave a planned social outing, as once again they are missing out because of something outside of their control. As such, many of these women have made changes in the form of diets in an attempt to gain some semblance of control, however this has made socialising through food a difficult experience for them. The women felt like they were an annoyance and a hinderance to others who could perceive them as frustrating.

> *"it was hard for a while there, especially being on the FODMAP diet -going out to eat… cos so much of your social life is going out to dinner or going out for lunch or going out for breakfast…so that was very isolating for a while and I'd get quite anxious going out to eat at places I hadn't been before" (Sally).*

> *"I ended up coming off being vegan purely because, it was very difficult and socially in a flat to be the only one, and we were all still trying to cook together and do things together and like they did their best, but it just was very awful socially" (Grace).*
>
> *"some friends certainly stopped inviting me to things because it was just too hard-basket for them I guess, or they felt like 'oh well we ask her and she always says no'…or 'she comes and she's already eaten because she doesn't wanna eat the food there cos she's not sure if it's gonna trigger her or not, so it's just easier not to invite her'" (Sonia).*

Another difficulty that was demonstrated was drinking alcohol during university. "*I had a lot of trouble socially in my first year of uni. I didn't have your classic like uni halls experience where you made lots of friends and like I don't drink either…I've never super wanted to drink but like having got all of this stuff I feel like I don't want to add more into the mix…So it meant socially I suffered cos everyone went out drinking all the time and I didn't drink at all*" *(Chloe).* Chloe felt that she did not get to experience the university lifestyle like others her age, partially due to the consequences she would experience if she did decide to drink alcohol.

Women reported feeling disappointed in themselves, let down by their body and annoyed with their endometriosis because they either could not attend planned outings or would have to leave in the middle of an outing due to feeling sick. Tania explained that she used to try and predict her flare-ups so she could plan her life around them, *"I would actually plan my social life around where I was on my period…Because I knew that there would be a chance that I wouldn't be able to do it"*. Feeling like the problematic one whilst out for food can lead to feelings of resentment and irritation towards themselves, and feelings of loneliness and being left out when they could not

do or eat certain things. Anxiety also surrounded these outings at restaurants in particular, as Sally explains *"some restaurants are really good and sometimes I would go up and be like "hey I've got quite a few food intolerances, here are the main things I can't eat, is there something that you can make for me?'... and some places would be really good about it, and some places would just be like 'well we can give you some hot chips' you know?".* This shows that it is not just anxiety and apprehension surrounding socialising and feelings of judgement from their friends and loved ones, but also of strangers such as wait staff. Being exposed to negative experiences over the course of their journey meant that they came to expect the worst, creating anxiety.

Self-sacrifice

There were times when the women felt that they would/should risk more pain and flare-ups for others as they felt pressured to function socially. Women limited or went without medication, ate food they would usually avoid, made decisions and performed activities which would cause their endometriosis symptoms to flare-up. The types of sacrifices appear to change depending on age. Those in their early twenties expressed a desire to be able to go out, drink alcohol, eat bad food, socialise with their friends all night, and just being able to behave young and recklessly, where Grace explained, *"I'm constantly in my head like 'oh you know just stuff it, you're twenty-one like live life' you know? Like 'just make the most of it'"*. Those who are a bit older express the desire of wanting to be able to socialise by eating food, having a glass of wine and exercising the way they were once able to, *"I mean certainly I do still have times where I'm like "well fuck, why can't I go out with my friends for their birthday and have a piece of cake and a glass of wine, and not feel like shit the next day" (Sonia).* Regardless of the types of sacrifices made the result is the same: they get to a point of frustration, isolation and yearning for another life, that it gives them the

incentive to sacrifice themselves with a flare-up for a period of time in order to release these frustrations.

Most of the women in this study follow specific diets in an attempt to manage their symptoms, which although they can provide relief for the women's symptoms, they can also provide difficulties in socialising and emotional satisfaction. As such, the women often want to neglect their diet, rules and medications in order to gain immediate satisfaction both for their food cravings and their ability to socialise, going out for dinner without having anxiety around whether they will be able to eat something on the menu, or having mindless fun with friends and family without needing to monitor what they eat or drink, which can be viewed negatively by others as well as being an annoyance to themselves.

> *"Like I used to be a lot stricter with what I ate and what I didn't eat… in an attempt to control my symptoms but I sort of reached the point where despite being super strict, it didn't solve the problem… And it's meant that I wasn't fully engaging and being fully present in social activities and like, you know, events that mattered to others" (Sonia).*
>
> *"I limit what pills I take if I want to go out and be social… So I know that I have to deal with…a bit more pain because I want to actually drink alcohol and be social with everyone else and not feel like…the sad girl in the corner" (Susan).*

Diets and food choices were not an immediate solution but had more of a long-term effect. Often the diets would work for a while and then stop working. In addition, the diets often further complicated their lives on top of the difficulties they already faced with endometriosis. Susan described *"the intermittent fasting worked really nicely last year [but not currently]… but then I think maybe I was having more…almost like more of the irritable bowel symptoms…?"* So while all the women had trialled different

diets at times, management of endometriosis was very individualised, based in time and space, and balanced with health or the risk of flare-ups.

Financial cost

Finances were discussed with five of the six participants, who agreed that to get above average medical care you had to get out of the public and into the private healthcare system. The cost of seeing a private specialist or even organising alternative care with elective medical professions can be astronomical, so health insurance was seen as very important. However, many of the diets are very expensive and other strategies such as holistic physiotherapy are not covered by insurance, so day-to-day management can be very expensive with no guarantee of short- or long- term success. The women tried holistic physio, neuro-linguistic programming, paying for advice from naturopaths dieticians, often with no success.

> *"I paid privately to go see a specialist over the hill in (town), and she was amazing and she basically said like 'we're definitely out of options' cos I'm not covered by insurance I couldn't afford the surgery with her… And that was $15,000 before she started doing anything" (Rebekah).*

Rebekah described her inability to be covered by health insurance as her endometriosis is a pre-existing condition, *"the hard thing is cos insurance won't cover me without a stand-down period…so I pay for everything myself and it's-it just feels like there's such a big gap and it's just so unfair, because like it's not necessarily about myself, but the amount of girls I know with exactly the same thing-all have the same stories, like, they can't get anywhere".* This is a fact of life for many, preventing women from being able to afford the care they need. Therefore women could spend a lot of money on treatment and management before they were even diagnosed, and depending on lifestyle, occupation and other life expenses some women would not be able to

maintain this for long and so would have to cancel appointments and suffer on their own, or struggle in the private system until they can afford it.

Diet and food choices were another aspect of the women's lives which were causing financial strain because of the types of food they had to buy, with gluten free food being particularly expensive. In addition to this, many of the diets require support from a dietician or naturopath such as the FODMAP diet, and often these women pay for these services themselves as they are not funded even with insurance.

> *"my dietician was really really helpful… in sort of talking about things that were low cost but still nutritious and like I can still eat… so yeah I've found that's really helpful, but the only thing with that is obviously it is expensive… so I haven't been able to see her as much as I would like" (Sally).*
>
> *"So that's [food intolerances] been a bit of-not a challenge, like it's actually been a lot easier than I thought it would be, but it's just…more time consuming, cos kind of like how much money, energy and time do you want to put into it?" (Grace).*

The cost of maintaining diets may be a deterrent to some women and perhaps part of the reason that some do not strictly stick to them, especially considering quite a few women in this study were students or were renting, which is a financial strain in itself. The women had to be creative and put a lot of consideration into their diets to find foods which cater to their intolerances and endometriosis, but which were also cheap enough that they can still afford to live. The cost barrier to accessing medical professionals and alternative avenues meant that the women could not make as many appointments for help as they desired. The women expressed feeling discouraged after having to spend their own money and time in finding a multidisciplinary approach that worked for them.

"it's depressing that I haven't found anything and it's depressing that there's loads of money down the hole" (Chloe).

"I think if I don't find a solution, kind of like coping mechanisms in the next year I would say I will start to lose a lot… I will get very discouraged, especially after spending like $300 at the naturopath, and going to all these places which aren't subsidised" (Grace).

The idea that the women had to sacrifice so much money to get adequate care is astounding. The financial burden is considerable but most of these women are in a position to afford this, some with help from their parents. For a lot of other women this would not be the case, further marginalising women's health.

Summary

This theme demonstrated that women living with endometriosis feel the impact in all areas of their lives. The women reported that endometriosis impacted work, school, their social life, relationships and their finances. The levels of pain and fatigue was mentioned as being the primary factor in this, however the financial burden of this disease is also substantial. The women in this study also described an important element in their lives was trying to manage their symptoms through diet and food choices. Some cut out an extensive list of foods (and alcohol) from their lives in the hopes these choices would significantly reduce their symptoms. However, as so much social life revolves around food and alcohol this leads the women to being excluded, feeling isolated and frustrated. The impacts from endometriosis can be alleviated somewhat through having supportive friends and loved ones but these people were not common. The discussions with these women revealed even other women did not understand endometriosis, leading to them sacrificing themselves and their health in order to make other people happy and to maintain relationships.

Lack of education, misinformation and misplaced hope

This theme unpacks how discouraged women were about perceived lack of education, knowledge, and up-to-date research from medical professionals and then a lack of knowledge by society including other women.

Normalising and dismissive

Both prior to and after diagnosis the women described their experiences surrounding their doctors telling them that the pain that they were experiencing, and the other associated symptoms were normal menstrual pain, normal ageing changes or a temporary issue that will be fixed by pregnancy. In general, medical professionals were described as dismissing the women's experiences without much thought and attributing them to other more common factors such as menstruation without further investigation as to other possible causes.

> *"I had spent so long with GPs saying like 'this is just normal…every woman gets period pains'" (Sally).*
>
> *"There was a lot of like 'oh, it's just period pain…you'll grow out of it…once you have a baby, you'll be fine'" (Susan).*

Consequently, women were denied sufficient care and had lengthy delays to any type of investigation and diagnosis. The pain and symptoms were positioned as something that they would need to learn to live with. The doctors' approach to discussing their disbelief with their patients appeared insensitive and blunt. Megan said, "*They thought I was just being a hypochondriac… 'all periods are supposed to be painful', but obviously not that painful*". The women felt there were superiority issues with some of the medical professionals, especially when participants tried to help progress the process of diagnosis.

"I went back to him about six months later and I said 'look, nothings really changed'… he literally shrugged his shoulders and said 'well I back myself as a surgeon so it can't possibly be gynae related'" (Sonia).

"So I got in with this specialist and he basically told me, that it can't possibly be endometriosis because I've had a surgery in the last few years" (Rebekah).

"Really difficult [experience with medical professionals]. Really just hard for them to have an understanding of what it is that we have…mostly just at a GP level…It was just a lack of knowledge, but then also a lack of belief as well…I often got told that maybe I was seeking drugs, you know even though I told them that I only take it if I really feel like I need to" (Megan).

Grace explained that she would rather doctors admit their lack of knowledge rather than dismissing the women and normalising their symptoms as it has such catastrophic impacts for the women, including with believability from others, causing doubt in themselves, being able to receive an answer to their problems and feeling validated within themselves, and going on to find useful management strategies. The whole process is delayed and cast in a negative light. Grace said, "*A part of me would kind of prefer them to admit like 'I'm sorry I don't know what it [endometriosis] is' over you know, 'this is just normal periods, get over it' sort of thing"*, as she would rather be able to move on and find someone more knowledgeable rather than waste time and resources to be told that she is delusional.

In addition, there is the frustration surrounding the use of diagnostic tools and methods, and the knowledge of the doctors who do not seem to stay up-to-date on the current information and studies on endometriosis. Susan described this frustration, *"Still blows me away that they even use that [internal ultrasound] as a diagnostic tool… Cos I mean I think after twenty something years we have figured out that it doesn't show up*

anything… But that doesn't necessarily mean that there will be no endometriosis when you cut her open….Makes me angry". There has been no progression in a field that desperately needs it according to Grace, *"change is slow, and it always has been and it always will be, and it's one of those things where you've just got to suck it up and like, it is what it is…But it's also very frustrating and so easy saying that when you're not hugely affected by it, like we are living with it every day".* This idea is reinforced by Rebekah who states that women's health and endometriosis is a prominent issue which disturbingly does not get enough attention or funding. *"There was a post about the-I think he was the minister of health saying that they weren't putting any money towards like women's health or anything like that… And then (town) DHB won't see anybody unless its cancer…Like that made me livid-because 'they're not urgent'…That made me so angry! And it's like 'you have no idea, and just because it's not an urgent medical condition, like mental wellness is a part of this illness and that is urgent'" (Rebekah).*

Blind faith

Despite the frustration with doctors, all of the women discussed the trust and belief that they had in their doctors. Doctors were seen as people who should have superior knowledge and information about women's health issues, including endometriosis. Despite their often-distressing experiences with doctors the women believed them. They took the doctors' word and opinion at face value because they are medical professionals who presumably are educated in all spheres of health and should have better knowledge than the women.

> *"I kind of thought it was endo, but I didn't want to push it because they had already told me it wasn't…and the doctor was supposedly an endometriosis specialist…so I trusted him" (Chloe).*

"we trust them because they're meant to be educated…we're going into an appointment knowing more about the illness than they do…like how can we trust them?" (Rebekah).

This blind faith meant further delays in diagnosis as the women accepted whatever the doctors said even if they disagreed, so it took longer for them to search for a second opinion. In addition to this, the women were often young when first seeking help for their symptoms, where due to the numerous disappointments they faced they had to learn to advocate for themselves and what they need. The women described that incorrect information was provided to them by their doctors, even portrayed to them as 'cures' when endometriosis is a disease with no cure. These cures suggested by their doctors gave the women false hope, being led to believe that if they did these various and sometimes extreme treatments, they would no longer have endometriosis. Upon realisation that this was not the case participants were often upset and angry. The women had gone through invasive, risky and life-altering surgery with no significant long-term improvement, meaning they felt they had wasted their time. On the other hand, some of the women described being told that there was nothing that could be done and this was just as distressing. Doctors just plied them with medication, which ultimately led to a sense of hopelessness for participants. This lack of correct information meant that participants had to conduct their own research and fight to be taken seriously, or they found out the hard way that what they were being told by doctors was incorrect.

"I had an appointment with my GP after I had my surgery, and she's like 'oh you know you'll be better now'…and that's just not how it is at all" (Sally).

"After like a hysterectomy was discussed with me…regardless of whether you know, you want kids or not, there's so many issues that come with it…which

wasn't discussed with me. It was just 'this will make you feel better' type thing" (Rebekah).

"there's still I think a lot of misinformation out there, even amongst medical professionals…'you should just get pregnant cos that will fix you'" (Sonia).

The women began to be more sceptical and cautious in information they were given, regarding any treatment methods or the portrayal of cures, where Chloe described *"it was exhausting trying new treatments and thinking they were going to work and then being so down when they didn't… I think it's a lot better to go into things being cautiously optimistic… don't expect things to work otherwise you're gonna get heartbroken".* The women did not want to keep getting their hopes up just to be let down and feeling worse both physically, mentally and emotionally than they did before. They described it as being emotionally draining and having a toll on their mental health.

The majority of women felt that they had to conduct their own research in order to find alternative treatment methods to help manage their endometriosis, typically because of the over-prescription of medication. The medication was often very strong, did not completely help their symptoms and, in some cases, did not work at all, or made the symptoms worse with side-effects from the continued use. The women also expressed fear over the long-term effects of taking strong pain killers and frustration that more information was not given to them about alternative treatments. Tania stated that *"I've actually healed that [digestive issues] myself because I didn't want to carry on taking medication".* Grace also told of how she was not given any alternative methods that she could try and implement, only medication in the form of hormonal treatments, *"I think that even though I have so much respect and appreciation for my specialist, I was kind of told only really the Mirena and Provera were the two options for me".* This meant she had to spend her own time and money finding alternatives

herself. Rebekah explained that being able to find her own alternative management methods especially in the form of food choices and diets was a better option than taking medication, as there is some semblance of control and knowledge of what you are putting into your body and that it is good for you, *"I'd much rather do diet than painkillers… at least with diet we know what's going in our bodies, but like the effects that all these painkillers have on the body… Like the long-term effects of being on these painkillers I'm pretty sure are a lot worse on the body than the food we put in".* Sally, Sonia and Chloe found the most helpful medical professional was a dietitian but as highlighted in the financial cost section the women had to pay to access this service. In addition, all the women did their own research on diets, supplements and recipes.

> *"I've done a lot of research myself on the benefits of zinc and vitamin c and magnesium and b vitamins, so I take those" (Sonia).*
>
> *"So I've made quite a big effort to do quite a lot of research, like online and stuff looking for kinds of recipes that people who you know are on similar diets make, that are good" (Sally).*

The other alternative treatments mentioned by the women included different forms of exercise and physiotherapy but the most commonly discussed was food choices and diet. Self-research included watching documentaries, reading news and journal articles, talking to alternative medical professionals as well as talking with people who have the disease and using online support groups. Sally described her sister's help in using diet as a tool to help with the symptoms as something she finds invaluable, *"also my older sister-the one who has endo… she's kind of similar to me in that she really struggles with gluten and dairy…so she's been able to teach me some good recipes and I just substitute the garlic and onion [personal intolerances] for things like chives and other kind of flavours".* Chloe and Megan use the support groups

and online forums to gain knowledge about diets and how and if they work, *"Sometimes I do research some things that come up in support groups like people…will like mention a diet and I will look it up" (Chloe).* Megan said, *"I'm on a couple of support groups… I find that helpful because I can read them and read what they're talking about and then like try and sometimes adapt what they're doing to what I do and changing my lifestyle".*

The women expressed that some of the food choices that they made were quite effective in helping to manage their endometriosis, particularly in conjunction with the medical approach. Sally described that with managing endometriosis *"it's definitely a very multidisciplinary approach, which I think that is something quite often overlooked".* Sally described that medical professionals often focus on the immediate fixes such as prescribing heavy painkillers but neglect to look into more long-term management or tackling the disease using multiple disciplines.

Misdiagnoses and a roller coaster

The majority of women in this study spoke of how many different illnesses they were diagnosed with either prior to or in addition to their endometriosis diagnosis, or even after a treatment where it should have been 'cured'. Many of their symptoms were seen to be stomach or bowel related issues such as IBS and constipation. Sally described all her diagnoses, *"I was diagnosed with Crohns, which was really random… tested for coeliac obviously, IBS which is a really common one…I got told a lot that it was just my polycystic ovaries… they thought I had like a stomach virus because I had a lot of the bowel-related symptoms".* Sally was also told she was suffering from chronic constipation which was why she was having such severe stomach pain. Chloe said *"I had a gastroenterologist who I actually really liked and he was really nice to me but he sort of diagnosed me with IBS but also said he didn't really know what it was"*. Grace

further described that she was misdiagnosed with IBS and that she had a doctor explain this to her where she said, *"I get really really bloated which makes me think, especially after the endo that my pelvic IBS isn't like a massive-they were saying it's not necessarily a disease, it's a symptom of something".* Soon after being diagnosed with the condition she educated herself and was told by others that IBS is not an illness itself but that it is a label given to those who have bowel issues. Grace observed this shows the lack of education and laziness that doctors have surrounding providing a diagnosis, that they stick with the most obvious symptom and give it the easiest label. Other women in this study were given a wide array of misdiagnoses throughout their endometriosis journey, some of which could have been plausible such as UTI's, kidney infections, kidney stones, back pain, and PCOS. Sonia described one diagnosis as ridiculous and borderline comical. Sonia said *"I went to see a gynaecologist and she was like 'well I think you just do too much high-intensity aerobic exercise, and you spend too much time on the spin bike and that's why you feel horrible'".* This was viewed by Sonia as being an absurd diagnosis that just shifted the blame back onto her, making her feel upset.

Lack of urgency

The lack of medical knowledge and importance placed on women's health and endometriosis means doctors often did not place any urgency on the issue. Women described their experiences as not being deemed important or urgent enough by medical professionals, and doctors acted blasé about what the women experienced and conveyed to them. Sally depicted that *"I guess I definitely experienced what felt like for me an urgent issue…There was a lack of urgency. And I think it was definitely a barrier in getting a diagnosis and being able to get treatment".* The delays meant that the women's voices and experiences were perceived as not being valued or validated and

they got made to feel like it was in their heads and that they were being dramatic. This also meant that treatment was not as efficient or frequent as it should be.

> *"the other barrier I think… endo is definitely treated as something that is very not urgent… the medical role really downplays how much endo impacts on people's lives" (Sally).*

Many of the women discussed that whilst being treated by medical personnel—or rather dismissed by them—they were treated rudely, were often belittled and made to feel as though they were trying to steal the doctors time from other patients who were more important. Susan discussed one situation where she was politely enquiring about her position on the waiting list for a laparoscopy, when a disgruntled medical professional spoke to her with abruptness and aggression, whereby any pretence of professionalism had disappeared in place of her almost personal opinion on the matter: "*I phoned them [medical centre] just last week and said oh you know 'just touching base to see how we're going'… She told me in no uncertain terms that I wasn't a priority… '[medical professional speaking] Yes well, we don't have beds for people like you'".* Not only did Susan lose hope of getting the treatment that she needed but she was treated with disrespect and made to feel as though she was being difficult when it is her right to receive adequate treatment.

Over-medicalisation – "drugs, drugs and more drugs" (Susan)

All participants in this study mentioned the copious amounts of medication that they have been prescribed in the past and present, which ranged from hormone pills to strong painkillers and opiates. The women also mentioned the casual approach medical professionals had in prescribing strong medications rather than finding alternative management methods. This is because of the 'medicalisation' that is pervasive in the medical field, where medicine has the power to define and provide treatment for any

illness and has social control over any abnormality related to the body (Conrad, Mackie & Mehrotra, 2010). The medical gaze is pervasive in society and gives medicine the authority over processes such as birth, ageing and death (Conrad et al., 2010), and promotes their progression in healthcare and pharmaceutical avenues to endorse and increase their profit margins and to increase consumerism in society (Conrad et al., 2010). As such, for most of the women, medication was the only form of treatment that they had been offered, where it was common for the women to be taking medication daily in order to get through each day and be able to function at work, university or school.

> *"I'm just on a whole lot of pain-relief like tramadol and codeine" (Megan).*
>
> *"I was taking oestrogen four times a day to counteract the bleeding whilst being on the Depo shot, so I ended up taking four times the amount of pills that I was usually taking just being on the pill" (Susan).*
>
> *"I take my ibuprofen basically everyday…I'll take panadeine…maybe it makes me mentally a bit more able to control it…Drugs, drugs and more drugs!" (Susan).*

Despite frustration at medication being seemingly overprescribed or offered as the only treatment option, the women depended on medication to have any semblance of life. The dependency and overuse of medication was brought up frequently in these interviews. Participants described taking medication more frequently than prescribed, even as a precautionary method in a bid to try and prevent symptoms from happening. It helps in *"taking the edge off" (Susan).* The women were also increasing their daily dose of medications in order to get through the day, as the women became resistant to the effect of the medication on their endometriosis. As such, they were experiencing higher levels of pain and so took more painkillers in an attempt to squander this, however

sometimes regardless of the amount and dosage of medications taken it *"barely touches the sides" (Susan).* This reliance on medication developed as the women felt they could not function without it and feared not being able to function in the future, leading to taking their medication pre-emptively.

> *"I used to take these period pain relief… I used to take them prior to getting it to see if that would help. And sometimes it would." (Tania).*
>
> *"today was a bad day so I was just like at the three and a half hour mark I was like 'I'm just gonna take it'" (Grace).*

Most of the women discussed their desire to cut down on or stop taking medication as they have been taking it for years and the side-effects that they experienced actually exacerbated their symptoms at times. Rebekah discussed her fear surrounding creating more issues for herself by taking medication which typically does more harm than good, *"I am so scared of taking those tablets because I'm gonna get constipated which makes the pain worse".* As such, many of the women wanted to stop using medication and were proactively trying to find more practical long-term methods of pain management such as making different food choices. As Sonia said, "*I guess trying to manage it as best I can with diet mostly… Rather than drugs*".

Advocacy – "you just have to fight, and fight, and fight" (Rebekah)

All participants in this study experienced having to fight for their stories to be heard, to be taken seriously and to get access to treatment. Many of these women's mothers also played advocate for them with their doctors, to help push and persuade the doctors to take their daughters disease and symptoms seriously, and essentially to do what the patient (and mother) believed was the best approach. The women and their mothers worked collaboratively to fight and get access to what and who they needed.

"I was in my doctor's office and my Mum pretty much demanded that we get a referral to a gynaecologist" (Sally).

"my Mum was a huge advocate basically for me… she was like you know 'it's not acceptable…That my daughter is in this much pain. Now I'm quite happy to walk in and say 'oi, I need this'" (Susan).

"I reckon I wasn't turned down as much because Mum was so pushy, because she was like 'no, this isn't normal'" (Grace).

Mothers were advocates for their daughters often because the symptoms appear when the woman is very young. Some of the mothers also had suspected endometriosis or had been through the situation with someone else that they knew, so they knew what to expect and what should be done. Sally explained, *"with my mum, as soon as I got diagnosed, she knew exactly what was happening. She was like 'right we are going to have a consultation with the gynaecologist who will probably suggest you have surgery so you've got to think about whether you want to have the surgery and it'll probably keep you out of doing much for this long'… so that was really good, having you know people around you who have supported someone who had been through it before*" (Sally). The women's mothers' knowledge was very much valued by the women in this study.

One of the participants in this study was lucky enough to also have a GP who had a thorough understanding of the disease, who tried to advocate for her patient with the specialists but due to rank and superiority of knowledge she was often ignored. *"And that's the hardest thing, like my GP…was so onto it, and she understands the disease so much, so well…and they don't listen to her, they don't even read my notes at this public hospital" (Rebekah).* This meant that despite having a medical professional on their side, the fight for their rights to treatment was still difficult. The women had to

learn to be knowledgeable and decisive surrounding what they needed, and to push this on medical professionals until they conceded, *"I think I've always just been quite stoic in being-I've been a bit of a pit-bull probably… And I'm also aware of the pain and where it is and what it is" (Susan).*

These interviews illustrated how much either the women or support people have had to fight to be heard, to be taken seriously and to be believed. However, having to fight and advocate all the time can be exhausting. Two of the women mentioned being tired from having to fight all the time, that their disease is already difficult enough to deal with without playing advocate too. *"I just kind of feel frustrated that…like there's so much stuff already, I don't necessarily want to be playing advocate all the time… Because it's so exhausting!" (Grace).* This highlights how poorly the system treats women with endometriosis and how much more work is needed to educate medical professionals.

Luck/Gratitude

Despite struggling to be heard and the constant self-management required to live with endometriosis most of the women mentioned being lucky and grateful. The things that the women felt lucky/grateful for in terms of their treatment were things that either happened purely by chance, were caused by advocating for themselves or provided for by their parents. These things included factors such as having private health insurance or money to pay for private health care, having someone to advocate for then, and/or accidentally finding a knowledgeable doctor who supported them.

> *"I was very lucky in that my parents had private health insurance… yeah I'm so lucky that we were able to do that and go through the private system… Because I know for so many people going through public it takes a lot longer and often you can't see the specialist that you want" (Sally).*

"Because honestly if it wasn't for her [Mum] I probably would only be getting the surgery now, realistically. I am really lucky in that my parents are really supportive financially" (Grace).

The women found that in order to receive adequate and efficient treatment they had to pay privately for more knowledgeable and specialist care, but they believed that this type of care should be available regardless of whether you are private or not. The doctors who are knowledgeable in the public system are few and far between, and as such finding one of these doctors who took them seriously and provided efficient care was considered pure luck.

"Even my GP as well, I mean I got lucky in that when I went back and saw my GP for like the fifth or sixth time, she was away so there was sort of a locum… A younger woman…a relatively new doctor. And I told her what had been going on, she looked at my notes and she was like 'I think you've got endometriosis'" (Sonia).

Lastly, the women were grateful and considered themselves lucky if they had any positive medical experiences and if they received the level of care that should be available to everyone. The negative experiences are more prominent and so to have a positive and validating appointment meant the women felt lucky.

"I am very grateful in that I was able to get really good professional care" (Sally).

"I do feel very lucky considering some of the stories and things I've heard from other people" (Chloe).

Other areas where the women felt lucky or thankful were in the area of self-management. This was such an up and down journey of trial and error that when they found something that worked they felt lucky that it worked for them. Sonia feels lucky

as she has always lived a very healthy lifestyle and so she has not found it as difficult as others have in adapting her food choices. Sonia describes, *"I've talked to a number of other women who when they start trying to remove things from their diet they really struggled…all the things that they can't have, whereas for me it wasn't such a big deal, so I guess I'm lucky in that sense, where I'm already used to not having all of these things".* What was common in the stories of luck was the comparison of themselves with other women who they felt were not so fortunate. Lastly, the women also took the standpoint that their endometriosis provided life lessons which were for the greater good despite suffering in the short term, where Sally stated that *"I guess in terms of my mental health, it's [endo] definitely taught me that there is a lot that I can be grateful for…despite all the shit things that go on".*

Summary

The lack of education and knowledge surrounding endometriosis highlighted by these women is astounding. There were stories of multiple misdiagnoses, poor advice given based on myths and misinformation, and no long-term or multidisciplinary support for these women. Medical professionals did not place importance or urgency on these matters, which the women attributed to them not having enough education around women's health and endometriosis, and due to disbelief and normalisation of period pain. All these factors are detrimental to women's health and contributed to the lengthy time to diagnosis. This meant women resorted to self-research on alternative methods and often were more knowledgeable and were in a better position to help themselves than doctors were. This was a shock to those who had initially relied on the expertise of their doctors who kept failing them. Women must therefore advocate for themselves and/or with a loved one to argue for their right to be taken seriously, and to get the best treatment which often leads them to be exhausted from the effort. However, all the

women had moments of gratitude when they are exposed to a positive experience. There certainly needs to be more education for all medical professionals and more research into this area. While all the women felt this was necessary, they also said it would not necessarily happen as money does not and will not go to women's health issues.

Judgement and Perceptions

This theme highlights the judgement, negative perceptions and scepticism surrounding endometriosis from others, including medical professionals, friends and loved ones.

'Sick person' and a burden

Half of the women in this study spoke directly about how they feel as though they are a burden to the important people in their life because of their endometriosis. This meant that the women typically felt the need to hide their disease, symptoms and how they were truly feeling from others. This was in an attempt to protect them and to feel as though they were not forcing their heavy load onto someone else. They did not want others to feel as though they had to look after them and they did not want to pressure people into that position.

> *"I became so withdrawn in some instances because of the pain and all the symptoms and…I didn't want to feel like I had to burden him [boyfriend] with a disease that he clearly doesn't know much about" (Megan).*
>
> *"I try not to talk about it too much because I'm aware that it's draining, and I'm aware that it's boring… exhausting for everyone'" (Grace).*

Some of the women isolated themselves when they were in a lot of pain creating a distancing in relationships. Sonia explained, *"There was a big distance that was sort of built up between me and my family and friends".* Sonia acknowledged that because of her feeling like a burden, this caused difficulties in her relationships which she was now

trying to mend and to be a bit more open with them. However, the women felt that others would not accept them and embrace their disease without feeling the weight of the burden, as they viewed themselves as not being worth it and as such had a low opinion of themselves. Sonia described some of these low periods in her life, *"you certainly go through periods where you sort of think 'fuck I'm a waste of space, and nobody really wants to hang out with me'… like it's all just too hard for other people".* This idea could have been reinforced by the fact that Sonia describes discussing her endometriosis with some of her friends, and feeling as though they were uncomfortable and unsure with how to treat her now due to the lack of understanding and knowledge that they have, *"I've tried to be really open to my close girlfriends about everything that has been going on with me…But I think they just can't-I guess naturally they can't wrap their head around it…I get the sense sometimes that they feel a little bit like they are walking on eggshells".* The women felt uncomfortable, as they expressed not wanting people feeling sorry for them and treating them as if they were fragile. As such, the women would rather hide their illness and how they were really feeling in order to not always be seen as sick.

The majority of the women in this study expressed wanting to be normal and not viewed as the sick person. People would try to be accommodating, which was helpful, but at the same time leads the women to feel insecure, isolated from the group and made to feel they are a nuisance. This is particularly the case in social situations which revolved around food. The women found that others were putting in the effort to make sure that they were comfortable and had food available that they could eat, which made them feel like a burden as special considerations would have to be made for them.

"when I first went on it [diets], it was really hard like going over to friends' houses, I used to take my own dinner with me cos I didn't want you know, their parents to have to struggle with finding something for me to eat." (Sally).

"it also impacts the way… that I eat and restrict… like going out and being able to relax around going to restaurants… and it sucks feeling like the sick person" (Sonia)

The women expressed feeling self-conscious about their endometriosis and subsequent food choices, especially where their friends and family would go to such great lengths to ensure that they were included, but this often had the opposite effect, making them feel singled out. They also expressed not wanting to live in a negative state of mind and feel sorry for themselves as there is nothing they can do about having endometriosis, it is all about finding a way to live with it.

"I find it easier for me personally to frame it not so much in I had-like I used to get very frustrated and angry like 'I have this chronic condition which prevents me from living a normal life and indulging in things that normal people can indulge in without consequence'. That used to make me really angry… I've tried to frame it in a 'I'm making a healthy choice for myself'… And just disconnect it a little bit from the chronic illness part of it, because I think the chronic illness side was making me feel kind of victim-y" (Sonia).

"I feel like everyone's then aware that I'm in tears and doubled over in pain and having to leave a [gym]class, and because its small classes then people are like worried, and I kind of have to be a bit blaze about it and be like 'well it's just life for me' because it is just life for me, but I don't want them feeling sorry for me" (Susan).

The women displayed their annoyance of constantly having to explain to others and fight for themselves. Grace discussed how she is tired of trying to explain her diagnosis to everyone, is sick of talking about it, especially because she is still coming to terms with her diagnosis, and she does not want to be that person who has to educate others all of the time, *"it's frustrating in that respect because you don't wanna have to explain yourself, and you don't wanna have to…like lay it all out".* In contrast to this, Grace also expressed that in some cases she thinks the only way to gain any understanding and empathy is to talk about it, complain about it, and to be seen by others as being sick, in order to spread knowledge and awareness. This has to be balanced with not feeling like a burden. Grace explained that *"it's also the fact that how do you get people to understand where you're coming from, and kind of empathise a bit, and it's like I guess I often don't even try because I don't wanna be that kind of emotional drain of a friend".* She felt that the only way to truly educate others is to be honest about the impact that endometriosis has, but that makes her vulnerable and exposes her to the label of being sick.

Dramatic versus disbelief

All of the women in this study described being perceived as dramatic typically due to misunderstanding and disbelief, with Sally stating, *"Sometimes it feels like nobody really gets it…and they think I'm dramatic and over the top".* This was most often displayed by others prior to diagnosis. Women were typically told this by medical professionals, teachers and friends, with a few of the women even being told this by their own parents, which impacted on their mental state and how they perceived themselves.

> *"I would tell my Mum and her attitude was 'oh well, suck it up and get over it' like 'stop complaining, you're such a drama queen.'" (Sonia).*

"not even my parents or like my school doctors believed that I was truthful…they thought I was just being a hypochondriac, that it's all in my head" (Megan).

"mums a bit tough you know, like 'man up' sometimes. And sometimes to be fair it is just like you do have to just man up and get on with it" (Rebekah).

"He [a specialist] basically told me that it can't possibly be endometriosis because I've had a surgery you know in the last few years, and it's definitely my bowels and its bowel pain" (Rebekah).

Having those closest to them not believe them meant that the women started questioning themselves, where they started to believe that maybe they were being overly sensitive about a normal experience. They learnt that they should live through the pain rather than doing something about it. The other women further described how this influenced their mind-set. Experiencing the disbelief from friends and family was described by the women as difficult to endure.

"I've had friends and stuff say 'have you considered the fact that it might all be in your head?'…you have so much doubt yourself, the moment anyone else casts doubt on it you're like 'oh my god, am I just being dramatic?'...like 'is my pain real or am I being super dramatic?'" (Chloe).

"I had the laparoscopy and it like obviously-I just expected nothing, like I honestly thought I was just a bit picky with pain, and I was just a bit weak… And I just kind of had to suck it up a bit more" (Grace).

This meant that in addition to fighting to be heard by medical professionals, they often had to do this with the most important people in their lives, often in their own homes. The lack of belief is strongly linked to the opinion people have that the women must be making it up, especially as Chloe described that when she received medical

results that failed to identify the problem this strengthened people's disbelief in her and reinforced the idea that *"I'm crazy and making it all up".* This led to the women feeling isolated as no one believed them, which led to negative emotions, where Chloe described, *"being able to just say to someone 'I have endometriosis', like when I used to tell people that I had random undiagnosed pain, they were like literally 'who cares'... not that they care that much about endometriosis, but at least they care a little bit".* Chloe also mentioned, *"it [having a diagnosis] makes you feel so validated, and I don't think you can underestimate how... important validation is".*

Summary

Endometriosis is not understood well by medical professionals let alone lay people, leading to judgement, negative perceptions and scepticism from others particularly during the long diagnostic process. Women were constantly faced with other people's opinions and perspectives about their disease and they reported being seen as melodramatic with this constant disbelief, often leading to self-doubt. Even once diagnosed women did not want to be seen as a burden or a sick person, but conversely wanted people to understand how the condition impacted on their life which meant being honest about the condition. This makes living with the disease even harder than it already is.

Community and connection

This theme discusses how women with endometriosis build and utilise communities for the purposes of connection and support, both in person and online.

Depth of connection and understanding

There is an instant connection and understanding amongst these women in both online and personal support groups, where they can empathise and counsel each other. This provides women with an escape from those in their lives who may not understand

their situation, and provides a safe space where others with endometriosis or who have knowledge about endometriosis are available to have open conversations with. Women can learn, share and discuss information and experiences which help them to feel supported and validated. As Sally says "*the community of people… Like you've never even met but are always there to have a yarn or to give advice or talk about what's worked for them and what hasn't… there's definitely like a real sense of understanding… Online especially*". These communities and platforms can also provide education on endometriosis, what it is, how to live with and manage it. The community gives them a space to ask questions and receive answers without the hostility, embarrassment, and superiority which often accompanies medical professionals' interactions.

The endometriosis community is an illustration of the instant connection, understanding and empathy that the women living with this disease have toward each other. This level of comradery is pivotal to these women who have faced years of disbelief from medical professionals, friends and family. Both the in person and online communities were viewed as a way to develop one's knowledge and understanding, whilst decreasing feelings of isolation.

> *"I've been through that time having no labels, and like okay endometriosis isn't curable but knowing that you have it means that you can like connect with other people that have it and learn how to manage it and all those different things" (Chloe).*
>
> *"Ooh I have endometriosis as well…as soon as you kind of learn that you're like oh! There's like a-you instantly kind of have an <u>understanding"</u> (Sally).*

These quotes portray a positive aspect of the endometriosis community whereby women are finally listened to and heard, believed, and are able to relate to others. This

level of understanding and connection with others that they may not have had before can be a surprising, comforting and rewarding benefit to joining the community, where Chloe states *"I think meeting other people with endometriosis and connecting with other people has been very positive for me".* It is worth noting that the endometriosis community is not just a place for women to receive support and empathy for their own experiences and issues, but it is also a place where their own knowledge and awareness expands, and where they develop and refine their own ability to empathise and show support to others, where Tania explains *"when I hear other people have endometriosis, my heart just breaks… Because it's so severe".* This demonstrates women's ability to relate to those in similar positions as themselves, which causes sadness, but which can also be channelled into ways to help others through connection and providing the ability to listen, help and guide.

Further, the support from these communities is also much appreciated and useful in their careers and workforce, with family members, colleagues, and in school and the medical field to help increase understanding. However, much of the time this support came from people who knew of women with endometriosis and had that first-hand experience to truly appreciate what the women went through.

> *"my boss, there was a man… And he was super understanding… And [he would] say, 'do you need to take a break?'. Like it just got to the point where he could just kind of tell… I think a big contributing factor for that, and it shouldn't be this way, but his wife had endometriosis… So, he definitely had a first-hand personal experience with it" (Sally).*

The women in this study discussed that they were more likely to be believed from either a woman with the disease themselves or someone who had personally known and witnessed someone having a flare-up. As such, these people had a deeper level of

understanding than those who have not had that type of exposure, and therefore would be more sympathetic to their plight and attempt to help them in whichever way they could. This was both a much needed and much appreciated factor within these fields, as they may not be able to function or perform to the level of others without endometriosis.

Confrontation and negativity

Although there are many benefits to the endometriosis community there are also some negative aspects, particularly in the online community. Some of the women in this study describe that at times the online community seems to have a larger focus on the disheartening and difficult aspects of the disease rather than highlighting aspects of positivity and hope. Some of the women in this study stressed that the online community and support groups have a dominant negative tone to the experience of endometriosis which overshadows the positives and glimmers of hope that may be expressed. This was accentuated by Grace where she describes that *"even though it is a support network, and there are some amazing posts and some things are so great, yeah, it's just like a year ago when I was kind of like in a worse mind-set and just over it all as well, and just had no solutions in my head, I didn't wanna be part of that" (Grace).*

Grace goes on to describe the sense of negativity and hopelessness that would exacerbate their own difficulties rather than help them. Grace says *"the thing with-I found even with the Facebook group, it's quite depressing sometimes…you know it's quite difficult… It's just everyone going 'I've gone through this and I'm just getting diagnosed but I've just had the surgery'-it's quite heavy… So, I had to leave a few groups cos I was just like 'there's no solution basically, there's nothing coming through to me right now that's inspiring me, that's telling me stuff's gonna get better'".* This demonstrates the hopelessness that can be pervasive in communities, where people are drawing upon and relate to each other based on the negative impact and distress caused

by a disease. The online forums and support groups seemingly accentuate these more so as the posts at the top of the news feed comment on negative general experiences rather than help with specific situations or treatments. There was also the view that people were seeking empathy and condolences by participating in the online support groups, rather than truly needing or wanting help from others.

> *"I just feel like posting photos of you feeling sick and sad, is fishing for 'ooh I'm so sorry that you're having such a bad day and such a bad flare-up' you know like, it's almost fishing for compliments but not compliments but you know, fishing for sympathy" (Susan).*

This was supported by Rebekah's approach to the online communities where she stated that *"I'm on a couple of support groups, like I just often sit there and read them, but I don't like I don't know like posting about it on Facebook, I don't know, there's just something I don't like about that".* These demonstrate the idea that although women find these support groups and forums helpful and beneficial in the sense that they can use them to generate ideas for the management of their own endometriosis, they find that posting on an online platform for everyone to see is attention seeking and as being almost inappropriate. Not all things shared are seen as necessary. Susan expressed *"I don't feel like the daily photos of her lying in bed with hot water bottles are particularly helpful".*

Further, the women found that the online community was a place of competition at times, where some women perceived other's comments to be gloating about treatments that worked for them, and taunting and exaggerating empathy and overacting surprise when discovering that the same methods did not work for others. In situations such as this the communities can lead to the women feeling discouraged, crushed and upset, where Chloe describes *"it's kind of hard reading all those things online about*

people who have surgery and then like miraculously they never have pain for the next like fifty years of their lives". Further, at different periods in their lives and their stage of endometriosis, the women appeared to perceive the community and comments about both positive and negative aspects differently, sometimes with frustration and feelings of sadness and being overwhelmed, and other times with hope, appreciation and eagerness. Chloe continues to depict one particularly negative and memorable experience she had which portrays some difficulties that interacting with others about such a sensitive and exhausting disease could create, *"I've had quite a few people say to me 'God like I can't believe this didn't work for you, like this works for most people, like 95% of people it will be good' and I'm like 'it's not helpful'…Someone posted something about Botox the other day, and everyone was commenting like 'Oh my God it literally changed my life, it was the best thing I've ever done', and I was like 'well, it didn't actually work for me…like it's very depressing but I just want you to go in there knowing that this is a potential thing that could happen, cos I didn't know and it ended up crushing me'…And this girl replied and was like 'yup I had it with (surgeon) and it worked for me' and I was like 'what?!…Like thanks for rubbing it in'".*

Summary

This theme explored how women with endometriosis in this study found online and in person support networks and communities predominantly useful and positive. This is because of the depth of understanding and the validation that others living with the disease can provide for the women, where they do not feel the need to have to explain or justify the way that they are feeling as they do with others in their lives. The online community in particular, provides useful information and an instant way to connect with and get advice from others, and this was highly valued by the women. However, there was a negative perspective of the online community where there was a

sense of competitiveness, over-exaggeration of emotions and an overall negative vibe of all of the distressing and traumatising experiences the women have were disheartening for some of the women in this study.

Mental and Emotional Impact

Living with endometriosis is more than symptom management, it also has an immense impact on the women's mental health and wellbeing. It is impossible to separate the mind and body for this disease and this theme covers how the women talk about the toll endometriosis has on their mental health.

Impact on mood

The women in this study discussed the negative emotions that come hand-in-hand as a result living with an endometriosis diagnosis. Rebekah exemplified this with the use of vivid imagery, *"You know like one of those broken-down cars? I'm one of those".* Rebekah believes she is broken, that something is wrong with her and she questions why anyone would want to be around her. The women believe that they are not important enough for others, they do not feel as though they are somebody that people want to be around, leading them to feeling lonely and decreasing their self-esteem and mood. All the women said they have often been sad, frustrated, felt low, and depressed at various stages of the journey. Tania even expressed thoughts of wanting to do anything to stop the pain, where *"sometimes the pain was so bad I was just like 'I wanna die'*".

> *"I'd say that in the first year that it happened, I would say I was like borderline depressed… But I've reached more of a point of acceptance, but it does get me down a lot" (Chloe).*
>
> *"it's really difficult when you have a condition like endo not to get really angry and really upset and why is this happening to me, and I've definitely had times*

like that…in terms of the bigger picture…I could spend a lot of my time and my emotional energy getting really upset and angry and frustrated about things that I have no control over" (Sally).

"I used to get very frustrated and angry like 'I have this chronic condition which prevents me from living a normal life and indulging in things that normal people can indulge in without consequence'. That used to make me really angry" (Sonia).

There were times when the women reported feeling particularly low. Many of the times it was prior to diagnosis when there seemingly was no-one listening or believing in the severity of the symptoms. Many of the women in this study also experienced anxiety at the beginning of their journey. Sally described that *"I have anxiety which…my psychologist and I definitely contribute some of that to endo obviously…cos it's such a you know, having to go through that whole process of no one believing you and that kind of thing. It definitely does impact on you a lot".* Being so young and experiencing symptoms that are not being believed and that are easy to cast aside made the women's lives difficult. As Sonia says *"prior to getting diagnosed I think I was in a really bad place cos no one was listening to me and it was just really bad and I didn't know why, I didn't know what the fuck was going on… I think yeah that was probably my darkest period of time prior to that".*

Women discussed how the impact on their mood is largely ignored by medical professionals with the focus on the physical body and not their mood or mental health. The women reported living with endometriosis as being on a journey with highs and lows, like a rollercoaster. The lows often were paired with times when the pain was severe but also with negative interactions with medical professionals. The women felt

like they were seen as drug seekers and attention grabbers leading to a further sense of isolation.

> *"I got called a drug-seeker by some Whoopie Goldberg looking nurse…it made me feel crap because they don't want to put any time or effort in, and it's hard because at the same time like we've got to accept the fact that so many people have it worse off, and we've gotta accept the fact that there's people much more urgent than us. But at the same time, it's almost like you feel unheard … unacknowledged" (Rebekah).*

The day-to-day management of the disease can lead to anxiety and low mood particularly when trialling new self-management strategies. Women were constantly monitoring, changing and working out management strategies of their own. This is particularly taxing when the women are also dealing with flare-ups and the consequent fatigue, which can lead to idleness with food management, *"I know myself, when I'm sick and just not in the mood I just kind of crave like all the other foods" (Grace).* The concern that the money and effort would not lead to any reduction in symptoms was common. Compounding this was often when their mood was low these strategies or things that helped (diet or alcohol restrictions) were ignored for stress relief purposes. These type of coping strategies often led to regret later on when the food-related choice made the symptoms worse.

> *"When you're depressed, I mean not depressed depressed, but you know very sad, and when you are really hormonal all the time, all you wanna do is eat really bad food… it's so hard to actually make conscious choices not to eat bad food all the time" (Chloe).*

> *"I was just trying to kind of cope with everything… I've just kind of been like 'enough is enough, I'm done living in this much pain, I'm done like kind of*

drinking and doing all of that to like numb it all out, I need to get on top of it'" (Grace).

The real concern for these women was that there was no psychological help offered to them to help cope with this disease, where Sonia explains *"there's a massive lack of resourcing and funding for these types of after-care… especially with something that impacts so many different parts of your body, like digestion, menstruation, sex, your social life, your ability to have babies, like that's massive and there really, really should be psychological after-care support and physical therapy as well"*. The complete focus of medical professionals on their physical body and often their physical reproductive body is very troubling. Any psychological help for the women in this study was self-funded and sought individually except for one woman, who had it mentioned by her specialist that it may be wise to do so.

Living with a disease with no cure

Living with a disease such as endometriosis is physically, mentally and emotionally draining, where most women in this study got to the point where they were completely overwhelmed and tired, where they just wanted to stop trying to manage and live with it. Because of this, living with endometriosis was viewed mostly as a negative experience and the women expressed a desperation and desire to find anything that would help alleviate some of the symptoms. The fact that there is no cure is heartbreaking for these women. The women described becoming so desperate that they would try any measure in an attempt to help their endometriosis, but this was overwhelming as there was an endless list of approaches they could take, where Sonia described *"I feel like I've tried everything under the sun".* Tania described her feelings of vulnerability, helplessness and exasperation with the never ending and never working treatments, *"It was like "God give me a break! [yet another option that didn't work]".*

Not being able to find an approach will lead the women to lose hope as they have already spent so much energy and tried to control the situation as much as possible and still could not find any relief from their suffering.

> *"she was telling me that she's been to see someone in Auckland and that she's going to occupational therapy, and I don't know-when I look back, yeah I probably would have tried that… Do you know what I mean? That's how desperate you get" (Tania).*
>
> *"surgery is obviously a trauma and causes scar tissue and adhesions and all of that jazz as well, so they come with their own problems… but yes, I guess I'm at the point now where…I have to do something…I mean everything's worth a go" (Sonia).*

The women reported anger and frustration, ruminating about why they had this disease imposed upon them and why they have to change their whole life in an attempt to manage their symptoms. The anger is directed toward the fact that they have this uncontrollable illness with no proven treatment or cure, where the effects on their lives have been immense thus far. There is frustration surrounding the inability to obtain the help and tools that they need to feel better, having instead to use trial and error. Sonia described her understanding surrounding the difficulty in developing a cure when the disease is so unique to every individual, however she does express that *"it does frustrate me that… there isn't anything other than birth control".* Here she is acknowledging the lack of research and dedication that has been expended so far in finding an easier and more helpful form of treatment for women with endometriosis. The women reported being worried and anxious about the treatment that was offered to them as a consequence of the lack of knowledge on endometriosis and described being fearful of the impact that would have on their symptoms and lives.

> *"I guess I'm also quite anxious around-so I was scheduled to have a hysterectomy two weeks ago, but I pulled out… because I was so anxious that, what if it doesn't work? Like I've had two surgeries already and…nothings helped" (Sonia).*
>
> *"they took my gall bladder out to see if that would help… so they took that away and it actually made it worse, so now I have to take these tablets every morning… that gets rid of the acid in my body… And they did that…it's their fault" (Tania).*

Sally also described that anxiety is ever-present surrounding her symptoms, *"Anxiety is definitely…one of the big parts of that is around my health in terms of like you know sometimes you get a really bad pain…and you know, you're like is this endo or is there something else wrong?".* She would question herself surrounding if she was feeling what she thought she was and whether there was something more serious going on that the doctors once again could not pick up on. This second-guessing and fear would be difficult to experience and rationalise as a young woman, particularly after having such negative experiences with medical professionals who did not know enough initially to diagnose with endometriosis, there is a sense of whether they know enough. There is a fear and anxiety that doctors are not doing enough but then fear and worry that the things they might do will not work. Even something that does help with pain can lead to terrible constipation and other side-effects which then causes pain. This endless cycle and rollercoaster of emotions is very difficult. This often leads to a feeling of hopelessness because of the constant failure of medical and alternative methods of management for their endometriosis symptoms. The women spent a lot of time and money trying to find management tools that worked and were disappointed when they did not help. However, sometimes the treatment or remedy would help for a short

period of time getting their hopes up to then to have them dashed when symptoms returned.

> *"I thought I was better now, and I thought I would get out and I could get on with things…it took three months and then blow me down one morning, I woke up and thought 'oh no, it's the same pain'. And I was just distraught… I was absolutely beside myself" (Tania).*

With regards to diet and food choices there are so many foods that could be cut out or implemented into their diet and the women felt frustrated and restricted in what they could actually eat as the possibilities seemed endless. There was also no guarantee the diet would work either in the short- or long-term. Some women described their frustration at having to change another thing in their lives on top of everything else. Grace spoke of the difficulty surrounding altering her diet, *"I guess in the short term it's a bit frustrating, cos it's getting used to cutting out a lot of food groups again".* Megan agreed with the frustration but she also mentioned a positive element, where she described that *"I just find it more annoying than anything, having to go out of my way and try and change everything… it's good that it's getting me on the track where I can eat healthy and I should be eating healthy but it's annoying that I have to go out and do it because of an illness that I have"*. This displays the challenge that the women may face in coming to terms with the idea that their food choices are another aspect of their life that they have to re-assess because of their endometriosis diagnosis. Some women do find these food choices easier to make and implement than others, where Sonia described *"whereas for me it wasn't such a big deal [trialling diets], so I guess I'm lucky in that sense, where I'm already used to not having all of these things" (Sonia).* The ease Sonia detailed that she has with changing diets is because she previously had a healthy diet and had cut many things out before. Food and diet in particular was a

strategy one women is sticking with despite it not being that effective for her symptoms, but because it is good for her health in general. Chloe explained *"and then it [treatment] didn't work and I was like 'what a waste of my time'…I mean I'm not like holding out too much hope, but I feel like it's a healthy lifestyle [going sugar free] anyway, so there will be some benefit from it"*.

It is okay to be upset

Endometriosis is associated with hormone fluctuations which accounts for the mood swings reported by the women, which is one of the many challenges that make living with endometriosis difficult. One woman brought up the idea of embracing her emotions and feelings, where she decided that she is allowed to feel whatever she does, and it is fine to express that emotion. Sally said*, "endos definitely taught me that even in the thick of the shit… There's always something that you can also kind of be grateful for. But also, sometimes there's not. And sometimes life just really sucks…And that's okay…I'm allowed to be angry and upset…and frustrated…we are constantly told like be positive, be happy. But up until a couple of years ago nobody had ever told me that it's okay to be upset and frustrated".* Sally explained that the idea that you had to have a façade of happiness and contentedness is reinforced by society, that she has been conditioned to feel a certain way so that others are comfortable. Grace also endorsed this where despite having to live with such a debilitating illness and struggling to find a way to live, she claims "*you're like 'no, the world has other plans for me'. And it's like 'okay that's fine', you have your down days and you have your days where you just cry and you're upset and that is a good thing"*.

Living with this disease has led the women to develop empathy for others particularly those with endometriosis. The women described feeling devastated for others who are only just beginning their journey and going through the diagnostic

process, especially when they are usually so young. It reminds them of their own experience and journey and how much of an impact this can have on various aspects of a woman's life.

"I get upset that so many other women have this same experience…that's the thing that really definitely affects me a lot emotionally" (Sally).

"you never wish it [endometriosis] upon anyone, you never go-like oh God I would never wish it on my worst enemy you know? But, it's also the fact that how do you get people to understand where you're coming from, and kind of empathise a bit" (Grace).

Two of the participants were older women who had lived with endometriosis for over 20 years. These two women expressed sadness that times have not changed significantly enough from when they were younger, that the same pattern, lack of knowledge and funding for treatment is still prominent in society today. Chloe states *"Yeah and there's not enough funding to do actual proper research either…it's a women's issue",* with Sonia elaborating with *"there's a massive lack of resourcing and funding for these types of after-care, things that are so necessary"*.

The women described getting angry and irritated with their bodies especially after taking their endometriosis management into their own hands through food choices and dietary changes and still experiencing symptoms. The fact that trialling diets and food choices often did not work was even more frustrating for the women as they were having to restrict themselves and could not eat and drink what they wanted.

"I remember feeling very frustrated cos it kind of felt like no matter what I was eating it was making me feel gross" (Sally).

Having to show self-control with food was extremely exasperating, especially where a lot of the women mentioned their love for food and their difficulty in

implementing these choices. In contrast, Grace suggested that this experience means she knows her body better than other women. *"And realistically, in ten years when they're all wrecked and they're all not able to get pregnant because they've been on the pill for ten years and they've done all this stuff, we are going to be in a space where we just know our bodies, we've known our bodies for over ten years like, we treat it so right… And even though it's frustrating but it takes a chronic disease to get you there" (Grace).* This message of eating well for general health reasons was important to Grace.

The unpredictability of endometriosis symptoms is what makes this disease so challenging for these women as there is no way to foresee their flare-ups. Even when they are in a good phase of the month in regard to menstruation, other factors can lead to a flare-up and exacerbate the symptoms to a level that disrupts their life. Exacerbating this is peoples lack of understanding about their experiences and what they have to deal with, isolating them further. One participant did mention that despite endometriosis being horrible and unfair, that others do have it worse off and it is more unjust for a small child to have terminal cancer than a woman having to live with a semi-manageable disease. So, although, this disease is viewed negatively and as being unfair, there is also the view that it could be worse. This was the position of Susan who decided to view the positives in her situation, *"there's always someone worse off… there are children that get cancer and that's really not fair cos they haven't lived… In terms of the grand scheme of life and stuff, endometriosis sucks ass but, you know like I'm not walking around attached to chemo drugs".*

Summary

This theme has demonstrated the mental and emotional toll that endometriosis can have on women. The predominant emotions expressed by the women were negative including isolation, depression, anxiety, hopelessness and stress. These emotions were

influenced by not only the endometriosis itself but their experiences surrounding the disease, many of which were caused by other people, particularly medical professionals. Living with a disease that has no cure and which is so detrimental to one's physical health and their ability to function can substantially effect their wellbeing, where a change of lifestyle and the exposure to judgement from others can be isolating, further exacerbating the effects from the illness. These effects are hard to adjust to, especially whilst having to endure high levels of chronic pain, and as such the women often experience low mood. Many have however now come to a point of acceptance, where they acknowledge that it is okay to be sad and upset sometimes and that what they feel in regard to their experiences are normal albeit difficult. There is a strong body and mind connection, where the physical symptoms can influence the mind and vice versa, which should highlight the multidisciplinary approach that should be taken to improve both of these realms.

Learning Moments

This theme focuses on what the women learnt from their individual journeys with endometriosis, which has led to their resignation, acceptance and current state of mind.

Process of acceptance

From the onset of symptoms, the women described having been on a journey with highs and lows, leading to an eventual state of acceptance or resignation to their illness. This is an acceptance of who they are, the disease that they have and where they are in life. Seven of the eight women in this study described being in a state of acceptance and/or resignation to their endometriosis, where they feel that there is nothing that they can do to change their situation and that they are stuck with endometriosis for life, but that they have become accustomed to it.

"I've reached the point where I'm like 'well, I can't make it go away'…so I guess I'm just sort of learning to live with a new normal" (Sonia).

"the way that I see it I guess is that I don't have control over it…and as hard as it is, it is definitely a process of accepting and sitting with… And just kind of make sense of it all" (Sally).

"it was a long journey of acceptance, that I think I am finally out the other side of. I still have dreams sometimes where I go back to swimming and everything's fine but I wake up and I'm so sad… But… yeah I'm definitely more at a point of acceptance now and also reaching a point of accept-like not getting your hopes up all the time I think is really important" (Chloe).

"I mean I struggle because I just have to accept that-I mean I see a therapist every other week… not specifically related to endometriosis but she's been really helpful… learning new ways of coping with living with endometriosis, cos it's never going to go away…learning to accept that I might not be broken and it might not ever go away but I just have to try and accept that this is what it is" (Sonia).

However, the acceptance of having endometriosis does not mean that the struggle was over or that the women gave up trying new strategies. The women would trial new things remaining cautious so as not to devastate themselves if it did not work as they did when they were younger. All of the women tempered with caution so as to not devastate themselves if it did not work. The women claimed that *"we all had to go through the process of like working out what it is and how we can deal with it and how to cope" (Megan).* They all put conscious thought and effort into finding ways to try and improve their symptoms through methods such as diet and exercise, where many

were ineffective or provided only the most miniscule of improvements. This was not a static process but part of the endometriosis journey.

Particularly regarding food choices, some women stuck with diets even knowing they did not help greatly with symptoms but for health reasons or in the hope that it might help in some way. Sonia has come to the opinion that *"I'm aware that you can cut out everything under the sun live really healthy and have other issues".* The women described areas of their lives that they had to adjust to and accept, and food and diet was one of these areas. Sonia rationalised that making the healthy choices in terms of food is beneficial to herself and makes her feel good regardless of the effect on her endometriosis. In contrast, Susan claimed that diet had minimal effect on her endometriosis which was temperamental and would flare-up regardless of what food she ate, and therefore she does not overly-restrict her diet.

> *"I've had to adjust is accept that I can't do high intensity aerobic activity anymore because that really does flare me up… in an intolerable way". "If I think about it from a personal health, wellbeing, positive choice for me as a person, to live my best life, that makes me feel a little bit more okay with it" (Sonia).*
>
> *"That's what I've got to the realisation, that actually it's got nothing to do with my food intake or what I put into my body, it's something already inside my body and on any given day it can decide to be an absolute asshole, or it can be an absolute princess and just be happy as" (Susan).*

Control and listening to your body

Many of the frustrations with endometriosis come from being out of control so women used certain methods of management to empower them and help take back

control of some of their symptoms. Being proactive and doing 'something' was seen as better than being a victim and doing nothing.

> *"for me pain was definitely my main symptom, and then my digestive issues were probably my second main symptom. But it was really nice to kind of be able to control them a little bit [cut out gluten and dairy] but I was still getting the main symptom" (Sally).*
>
> *"I've tried every sort of potion and lotion under the sun, didn't really work but it felt like I was doing something so I went along with it" (Sonia).*
>
> *"endometriosis and the symptoms are so unpredictable…controlling what I eat and knowing what I put into my body, gives me a sense of control over what's happening to me" (Sonia).*
>
> *"it's such a mixed sort [dieting for illness] because it's so positive in the sense it gives me control…of every day… Like, every single thing that you put in your mouth like 'okay cool, this is either going to make it better or make it worse'… it really is quite empowering, like you being able to control that" (Grace).*

The women described that being able to conduct their own research and implement their own food and diet choices was empowering, that they were making their own decisions and making an effort to help themselves rather than relying on others. Grace describes that *"you really just need to take charge of your illness".* There are many negative mental and emotional impacts of endometriosis so 'taking charge' made the women feel strong and useful. Being in control helped the women take back their bodies and look after themselves better as a result, sometimes with the additional benefit of reduced symptoms. Some of the women said living with endometriosis has made them take care of their physical and mental health with the realisation that taking care of yourself is not a flaw.

"I take care of myself a lot better than you know a lot of my friends do… just in terms of like, getting enough sleep and eating as kind of well as I can… and looking after my mental health… It's definitely been a big factor in making sure I take good care of myself" (Sally).

"to be honest I'm like happier in the sense that I can wake up in the weekend and just look after myself, like I am kind of finding some joy in that and I think it will get better the healthier I feel as well, and the less painful my endometriosis is the more it kind of feels worth it if that makes sense? (Grace).

The women have learnt to become aware of and in tune with their bodies, which included acknowledging destructive behaviours and learning what triggers flare-ups. Grace explained that *"if you really think about it, I'm twenty-one, you're twenty-four, we are still so young in our lives yet we are so aware of our bodies and we are so aware of what our bodies are capable of [in comparison to those without endometriosis]".* She explained that the disease gives us the knowledge we need to look after ourselves at such a young age and which will benefit us in the long run. Therefore, becoming self-aware and learning how to manage her endometriosis and the other elements in her life has made her feel better about herself and more in control.

The women took their own health challenge upon themselves as they felt that no one else was going to care enough to significantly help. Self-care and self-management were for these women about a sense of control, resistance to medication and the medicalisation of endometriosis. The women explain how important it is to listen and have knowledge of your body in general, but particularly when suffering from endometriosis. Endometriosis is a very individualised disease and so to be an advocate for themselves the women described how important it is to be aware of their bodies.

"I kind of follow what my body feels like" (Susan).

"that I just know myself and when I work out I feel better and I'm less bloated and in less pain" (Grace).

"I don't think there's been, at any point really there hasn't been anyone suggesting or wanting to talk to me about specific emotional or social impacts that it's had on me and how I can manage that aspect of it… All of that sort of stuff I sort of sort out for myself" (Sonia).

Many management methods are introduced by the individual rather than a professional, so it is important to be able to monitor these themselves. The knowledge that they have on their bodies also means that they will be better able to communicate with professionals, where they can advocate for what is happening and what they need, which hopefully will increase their chances of being listened to. Further, being able to gain some semblance of control over their physical body and their symptoms counterbalances with their mental and emotional health, empowering the women, improving their mood, state of mind and hopes for the future. Being able to control and improve the body leads to improvements in their mind and the anxiety, stress and sadness that appears hand-in-hand with endometriosis. The learning moment is the realisation that the women are the experts in their own bodies, their own disease and part of the acceptance/resignation comes from this awareness, so this requires them to listen to their bodies, take control and balance mental and physical health.

Positive experience

Five of the eight women were able to find the positive aspects to living with endometriosis, where the other three were still in a place of negativity surrounding their endometriosis and their journey. This appeared to reflect severity in cases, where the three women who have a negative view of endometriosis were the women with the more severe and life-changing elements to their journey. The five women who have

adopted a positive perspective explained that the positive aspects were better knowledge and understanding of your body, you can relate to others in a way that you could not before, taking on healthy diets and taking care of themselves, and a new awareness of what others may face living with a chronic illness. Some of the women described the very few positive experiences that they had with medical professionals. The women valued these positive experiences even more due to the many years of struggling to find a doctor that would believe them let alone being able to sufficiently help them.

> *"we've had the like benefits of going to dieticians, they've tested your blood to see what your body needs, like naturopaths are looking at your hormones, you're medicating, you're going to see counsellors, you actually are valuing yourself the way that bodies are supposed to be valued" (Grace).*
>
> *"That was really incredible actually [seeing naturopath]. I came out of it like super kind of overwhelmed…but also like really really positive" (Grace).*

The key positive aspect of endometriosis was how it made the women feel as individuals, as strong women who have proven that they can overcome and deal with anything. It has therefore allowed the women to feel healthier mentally, where they gained clarity and a sense of self through living with endometriosis and became physically healthier as they made dietary changes.

> *"there's a positive aspect… Like it definitely has made me a stronger person" (Sally).*
>
> *"I guess a positive as well is its sort of made me more aware of like the food that I eat and the quality of the nutrition that goes into our bodies and the impact that that has on us, not just physically but mentally as well" (Sonia).*
>
> *"it's such a mixed sort [altering diet for endometriosis] because it's so positive in the sense it gives me control" (Grace).*

Another positive aspect that the women described is that it allows women to meet others with endometriosis and those who help support someone with endometriosis and this opens up a dialogue for women's health and endometriosis in particular. It has allowed women to gain empathy and guidance from those who are living with the disease, whilst also having the ability to do the same for others, and it has also allowed women to grow closer to their loved ones as they share intimate parts of themselves and they learn what it means to live with endometriosis and constructs their own reality.

> *"Oh the positives…definitely the community of people around, and even just like talking to girls" (Sally).*
>
> *"I think meeting other people with endometriosis and like connecting with other people has been very positive for me… I've liked that part of it." (Chloe).*

Summary

Endometriosis is not just a burden on the women but has given them the push to learn and grow not just about their endometriosis but also about themselves as women too. The women's journey with endometriosis taught them many things and has developed them mentally and emotionally over time. Out of such a debilitating illness and difficult experiences, the women were able to persevere and learn new things about themselves. The women placed value on being able to obtain knowledge, gain control of their situation, maintain balance in their lives and their endometriosis from a positive perspective. They have learnt that although endometriosis cannot be cured, they can implement strategies and take a positive stance in order to lessen the difficulty in their ordeal. As such, the women in this study expressed that they became better, stronger and more capable women who have more empathy and patience for others. They went

through this long journey of acceptance and came to a point where they now know what their bodies want and need and are proactive in getting it.

Chapter Five

The purpose of this chapter is to link the findings in this study with previous research that has been conducted, highlight new information, and contribute to the knowledge available on endometriosis in NZ. This chapter will conclude with a discussion of what future studies should focus on.

Discussion

The aim of this research was to provide a platform for women with endometriosis to speak of their journey with the disease and the multiple ways it has impacted on them and their lives. The focus was on the self-management of endometriosis using food and diets. The framework of feminism was chosen in order to privilege the women's voices and to critique the medical system which constrains and categorises women into one or both of two groups: problematic reproductive bodies or hysterical women with bad periods (Kaur et al., 2018; Kristjansdottir et al., 2018). There were two interviews with each woman that allowed them to share their experiences since the onset of symptoms until the present day, with discussion on how they are managing their symptoms through food choices and other means. The intention was to provide the women with a safe space where they felt they were being heard and understood and part of this meant disclosing how I too live with this disease. This study focused on two research questions which were "How do women live with the symptoms of endometriosis and how does this impact them?" and "How does food/diet effect the symptoms of endometriosis in women and consequently their lives?". Thematic analysis was used to analyse and interpret the data.

This research revealed six key themes which were: impact on life, lack of education, judgement and perceptions, community and connection, mental and emotional impact and learning moments. These six themes encompassed all areas of

the women's lives, including the medical treatment and interactions they had, relationships with others, impacts on their daily functioning in both a mental and physical capacity, and long-term effects such as the women learning to live with and manage their disease.

Impact on life, quality of life and pain

Endometriosis impacts on all areas of women's lives from work, school and university, to their ability to perform everyday activities such as cooking and cleaning, socialising, and maintaining intimate and other relationships. The profound impacts on the women's lives were influenced by the many symptoms of endometriosis and the side-effects of treatments, however the most debilitating symptom for the women was chronic pelvic pain. This has been found in other research on endometriosis where women describe the waves of crippling pain which are sporadic and difficult to manage, and the immense fatigue that goes along with this (e.g. Culley et al., 2013; De Graaff et al., 2013; Facchin et al., 2015; Huntington & Gilmour, 2005; Moradi et al., 2014; Whelan, 2007; Young et al., 2015). There are two aspects to pain, firstly, it is difficult to predict flare-ups leading to uncertainty and frustration. Secondly, the pain stops the women from performing day-to-day activities impacting on work, school, university and social life. This study portrayed the trauma associated with living through such excruciating and debilitating pain, often not being able to alleviate symptoms with strong medications, meaning the women would have to endure it. On top of the debilitating pain there is the aftermath of it, where there is anxiety surrounding when a flare-up will next happen and being exhausted and feeling low from having to suffer through the flare-up. This study shows why women are so desperate for a cure, or at least a more reliable form of treatment method to help manage their pain and other symptoms. Huntington and Gilmour (2005) found that pain affected all areas of

women's lives and impacted on their state of mind and well-being, leading to some women feeling that if they did not get on top of the pain they would rather die. One woman in this study also mentioned wishing she was dead at times whilst having a painful flare-up. The desperation of dealing with pain and the anticipation of future pain illustrates a reduced quality of life as physical health, activity, mood and mental health is all effected (Fine, 2011). Compounding this is the women's tolerance and capacity to cope with the pain during their flare-up, where if they do not have any effective pain management strategies in place this can cause desperation and as such a dependency on strong medications (Poulin et al., 2016). Other research on chronic pain has found that the unpredictability of pain is very problematic leading to anxiety and fear (Crowe et al., 2017)

This highlights two key concerns. Firstly, pain management of endometriosis is complex as women personalise their pain medication use both in response to pain and in anticipation of pain so that they can function. This has been shown in research by Wright (2019) which showed women became lay experts in endometriosis, personalising their pain treatments and other self-management techniques, and Crowe et al. (2017) where chronic pain required vigilance because of their lack of control with such illnesses. Secondly, that to treat endometriosis solely as a physical disease is problematic as it ignores how much of life is impacted on by endometriosis and how significant the resulting impact is on mental health and mood. Endometriosis is a disease that is highly medicalised, largely in response to pain management and has an almost sole focus on the physical body. The medical model emphasises biological measures of pain privileging dominant gendered notions of pain rather than acknowledging women's subjective experiences (Whelan, 2003; Wright, 2019). This is

one of the main contributing factors to the continued disbelief and dismissive attitudes of medical professionals leading to the normalisation of all period pain.

Medicalisation and resistance

This medicalisation was resisted by these women in an effort to take control of their lives and resist pain medication. One way the women did this was by utilising self-research and self-management strategies. The use of self-management strategies for those living with a chronic illness is pivotal in the transition of being able to live with their chronic illness, to gain a sense of control and empowerment by taking a direct and autonomous approach in trying to manage their symptoms (Kralik, Koch, Price & Howard, 2004). Gilmour et al. (2008) found that for women with endometriosis, the lack of a cure, adequate help and the inability to function in their lives meant the women decided to research and implement a variety of alternative management methods, which could help manage their endometriosis and hopefully lead them into remission. Culley and colleagues (2013) found that some women used alternative methods in addition to medical assistance, whereas others rejected the biomedical approach entirely and took their treatment into their own hands. None of the women in this study completely ignored medical methods—although some wished they could—but all of them used a range of self-management techniques, including diets, and bemoaned that there was no support provided for their emotional and mental health. The women expressed their concern over the long-term effects of the medications and stated that this was a key reason as to why they made the decision to start managing their disease for themselves. There are very few options for women beyond resistance through self-management strategies, discovering new knowledge and trialling methods to help manage their symptoms. Research is one way for the women to initiate ownership over their endometriosis, and to make choices and changes that would hopefully benefit them

(Cox, Henderson, Wood & Cagliarini, 2003). Taking control through self-management has been shown to be beneficial for people with other chronic health conditions such as cystic fibrosis, diabetes, and inflammatory bowel disease (Schmid-Mohler, et al., 2018; Sweeney et al., 2019; Widayanti et al., 2019). None-the-less, endometriosis is a gendered disease and as such comes with additional barriers such as the fact that women are largely treated as reproductive bodies (Kaur, et al., 2018).

The women in this study used food as a way to gain a sense of control, manage pain, cope with everyday life, and resist pain medications. While food and diets were not the only strategy that these women used, this was the focus of this research project. All the women in this study had used multiple diets over various time periods to help manage their symptoms (Appendix K). The constant trial and error of different diets and strategies was time consuming, exhausting, expensive and often did not lead to symptom reduction which was difficult to deal with. Other research has shown that lifestyle changes including with diets, food, and supplements have been used by women with endometriosis with some success (Halpern et al., 2015; Santanam et al., 2013; Velasco, 2019; Wong et al., 2016) There is no one diet that seems to work for all women, further illustrating the individual nature of symptom presentation for endometriosis. Regardless of the effectiveness of each food choice or diet implementation, the women commented feeling empowered that they were being proactive and doing something to help themselves, by eating healthy and taking care of themselves. Also, they were not just being a passive victim waiting for someone else to fix them. The relationship between food and health is illustrated by these women where often the women stayed on diets which had limited effects on symptoms in order to be healthy. This seemed to have a positive impact on their health, both physically and mentally. The women reported they felt healthier, felt more prepared for a flare-up and

for some women the flare-ups were less frequent and intense. Often this trial and error of diets let to a new sense of body awareness that the younger women were proud of in comparison to their less aware friends.

A fundamental finding was how much of the women's lives revolves around food and alcohol. The fact that food and endometriosis are fundamentally socially constructed is largely ignored in other research. This research has demonstrated how being on restricted diets and not drinking alcohol lead to the women feeling isolated, lonely and frustrated. Socialising, university, work, and important occasions were either avoided, or restricted because so many of these activities involved alcohol and inflammatory foods. So, in addition to being unable to attend events due to extreme pain and fatigue these women were further marginalised and labelled as dramatic, annoying or sick, because of their attempts at adhering to diets and food groups which were beneficial for them but perhaps a hinderance to others. Relationships with friends and family were impacted and women felt they were not invited to social events as *"I just can't eat anything…it's made me a really fussy eater now" (Tania)*.

At times in resistance to 'restriction' and having to show self-control all the time, women sacrificed their health and risked flare-ups in order to socialise, fit in, and appear normal. This typically involved allowing themselves 'bad' or comfort foods such as having cake or a class of wine. Women wanted to fully participate in social events without worrying about being sick, their medication and other elements like dietary restrictions, so would relax self-management strategies. Despite this, the women more often than not avoided social outings because they felt left out at these events or they would typically have to leave anyway because they became sick. By limiting medication and neglecting their usual cautionary actions they were able to fully engage in the moment without anyone having to accommodate them and leading them to feel

like a burden or feeling left out. The women in this study often ate as healthily as possible with some following very strict diets. This meant that the women got to the point where they wanted to cheat on their food choices by splurging on their favourite food items, whether it be because there is a special occasion and they wanted to celebrate and forget about their endometriosis for a short time, because they were craving specific foods, or because they were feeling low. Women described that endometriosis already effects their lives so much that being able to sacrifice areas in their lives when they feel the need is important to them, in order to have control over how they live their lives and to maintain balance of living a cautious life with their disease but also a happy one. The women also mentioned that being able to do what they want and pretend to be normal for a little while did help them cope mentally and emotionally with the fact that they have to live with this all-consuming disease.

The women also sacrificed themselves by not taking heavy painkillers in order to concentrate, performing activities such as high-intensity gym sessions or having sex with their partners, all of which lead to flare-ups. These were seen as occasionally necessary for the sake of their intimate relationships, friendships and for mental health reasons. This idea of the women having to sacrifice themselves was positioned as balance: balancing physical health with mental health or balancing risk of flare-ups to try and gain something for themselves. Occasionally the women felt pressured or obligated to do things that would cause flare-ups due to gendered and social ideals and expectations. The women experienced painful sex that lingered afterwards and so choose to not have sex often. However, there were times when they felt that their partners needed sexual gratification and they wanted to be intimate, and so endured it for the benefit of their partner and for the preservation of their relationship. This need to self-sacrifice encompasses all areas of the women's lives where they are trying to find a

balance between being the sick person and needing to be cautious, with living their lives the way that they want to. Whittemore and Dixon (2008) also discuss self-management of chronic illnesses, where they should prioritise mental and emotional health by balancing "the demands of the illness and one's desired life" (p. 178).

Despite the negative aspects of living with endometriosis this study found that the women expressed feeling lucky or grateful whenever they were exposed to a positive experience in relation to their endometriosis. This has been found in other research on chronic illness as people adjust to living with the condition and become resilient in the face of their adverse experiences, leading them to develop a more positive lens about their situation (Kralik, Loon & Visentin, 2007). What is interesting is that the women felt lucky when they did have positive medical interactions or a good doctor, because most of the women's interactions were negative and subjected them to disbelief, misinformation, and poor healthcare. As such when a woman finds herself being treated fairly and adequately, they expressed feeling so lucky that they finally found a knowledgeable and accommodating medical professional. The women also felt gratitude whilst comparing themselves to other women with endometriosis but also felt sorry for them, particularly for those young women who are only at the beginning of their journey. Their gratitude of their situation was also heightened because of the view that other people are living worse off, that there are children with cancer in this world. This thought was echoed by patients with either osteoarthritis or ischemic heart disease in a study by Silverman, Nutini, Musa, Schoenberg and Albert (2009), they also felt grateful of their situation and relieved that they are not facing worse situations. The women in the current study described also being grateful for having their parents support and help in advocating for them. Women also counted themselves lucky if their parents helped them financially or if they had health insurance, as a good level of

quality of care without this was seen as difficult. Also, as the disease is so individualised women felt lucky if they found a strategy that worked to help them manage their illness. While it is encouraging that women can see a positive aspect to living with endometriosis, it is a poor reflection on the state of our medical system, where good medical care should be the norm, not simply a matter of luck.

Gendered disease and a journey

Previous research has highlighted how dismal the average length of time to diagnosis is for women with endometriosis (Jones, 2004; Moradi et al., 2014; Young, 2015). This study revealed that these women experienced long and arduous journey's to diagnosis primarily caused by the difficult relationships that women have with medical professionals. The average length of time to diagnosis for this study was ten years, however it should be noted that the older participants (over twenty-five) in this study had a lot longer diagnostic delay ranging between eleven and twenty-six years, than the younger participants (younger than twenty-five) which ranged between three and eight years. This likely shows the growing awareness and new medical developments surrounding women's health and endometriosis which is promising but still problematic. However, there is still the ongoing issue of a lack of education for medical professionals as this study highlighted how often women had been exposed to inexperienced and uneducated doctors, who dismissed and normalised their symptoms as being female problems and something that every women experiences. If not, they provided the women with misinformation which was more myth than fact, demonstrating the lack of training in women's health, in particular about endometriosis.

The need to fight and advocate for themselves (or have others do this for them) was used by all the women in this study. Moradi et al. (2014) also found women used words such as fight or battle to describe the process. This shows the difficulties for

women in gaining a diagnosis and adequate treatment, which appears to be due to a combination of factors: the health system, poor education and knowledge of medical professionals (with very few exceptions), and gendered notions towards women as reproductive bodies. Grace and MacBride-Stewart (2007) says the female body has been socially constructed and pain is normalised as female bodies were built to endure pain in bearing children. Thus, all pelvic pain is deemed natural, what women should expect, and as an inevitable part of being a woman to fulfil this role within society (Grace & MacBride-Stewart, 2007). Couple this with the fact that the medical field is highly masculinised, there is often a disregard of and demeaning attitude towards women's experiences and voice, privileging male opinion and knowledge as it has consumed medical practice (Huntington & Gilmour, 2005; Jones, 2016; Manwaring, 2018; Young et al., 2018). This then led to what the women described as a 'lack of urgency' and minimalist 'treatment' methods in the lead-up to their endometriosis diagnosis. There was often the neglect of relevant symptoms for the more obvious and easier to address symptoms such as bowel related issues, more often than not leading to misdiagnoses of IBS or other gut-health related issues. Being exposed to such experiences, the women described developing a negative view of self and started to believe the doctors perspectives that their symptoms were all in their head and that it was normal. Mortimer (2002) also found that these poor interactions impacted on women's mental and emotional health.

As well as disbelieving doctors, unfortunately, all the women discussed losing friends, having sceptical family members and unsympathetic work mates. Often women with endometriosis have looked to online and personal support groups for research purposes, understanding and knowledge (O'Hara, et al., 2019) and this was the case in this research. It should be noted that this study found that support groups have both a

positive and negative side. In the support groups there were many gloomy stories surrounding what other women experience surrounding their endometriosis. This does make the women feel sad for those having to endure it, however it does make them reassess their lives and where even if they have had bad experiences, they know that it could be worse and so they felt grateful. Rogers, Gately, Kennedy & Sanders (2009) found this for other people living with chronic illness, where they employ downward comparison of themselves to regulate how they are feeling, by acknowledging that they are in a better situation than others. This is done in order to stay positive about one's self and better cope with their illness (Rogers et al., 2009). However, some with chronic illnesses also use upward comparison which is where they compare themselves with those in a better position than themselves in order to gain a sense of hope and comfort (Rogers et al., 2009). This could also explain why some women in this study valued the use of social media community groups to get advice and be re-assured about how they are feeling and what they are experiencing. In contrast, the women also expressed that online support groups were negative where people were seen as attention seeking and as acting inappropriately. This was also found by Dearing (2019) who suggests there are two types of users of online chronic illness support groups. The first uses the support group to mentor others, leading to a sense of purpose. The second is where individuals use the support groups in a supplementary capacity, where despite utilising the platform, these users found the negativity expressed in the community as annoying (Dearing, 2019).

Endometriosis is often described by women as a journey, first to diagnosis and then to a sense of acceptance or resignation, but also that the journey is on-going and like a roller coaster. The impact of endometriosis on these women filters into all aspects of their lives and as such requires adjustment to a new sense of self and identity,

everyday activities and goals for the future. Biographical disruption is when a person registers pain and suffering as their norm despite the fact that it causes disruption in their lives, in which they have to rethink and re-frame their situation and find ways to cope with their illness (Bury, 1982, as cited in Williams, 2000). It is common with chronic illness that individuals progress from a stage of questioning themselves and why they have been inflicted with an illness to accepting, normalising and utilising management methods (Williams, 2000), to then developing a sense of hope for the future - all of which was demonstrated with the women in this study. Facchin, Saita, Barbara, Dridi and Vercellini (2018) suggested that endometriosis disrupts all aspects of women's lives and through a grounded theory study suggests a theory of experiencing disruption versus restoring continuity. Facchin et al. (2018) found that the women who could see the positive aspects of endometriosis had found a way to "live with it, which led to a restored sense of continuity" (p. 542), where they adjusted to their illness, and that this process was important at all stages of the journey. The women in the current study agreed with this where they described being on a journey that although initially had negative associations and they had 'why me?' thoughts surrounding having endometriosis—and at times they still have these moments—they perceive their experience positively overall. Endometriosis made them stronger more independent women who can overcome many challenges. They explained that having a greater knowledge and awareness of their body was empowering and made them better people because they treat their body the way it should be treated, this is especially with the younger women where this likely would not have been the case if they did not have endometriosis.

Much of the literature on endometriosis takes a deficit approach and highlights the purely negative aspects of living with endometriosis (e.g., Jones et al., 2015). While

endometriosis is a chronic health condition with no cure, women can get to a more positive place of acceptance. What does need to happen for the women to get to this place has also been underscored in this research. Firstly, the lack of education of medical and other health professionals about endometriosis. Kristjansdottir et al. (2018) discusses how those living with chronic illnesses should be encouraged by health professionals to recognise their strengths in order to empower themselves, better cope and self-manage. This then requires a change from the dominant biomedical model and medicalisation of this disease to a more holistic approach to treatment. Secondly, the diagnosis process has to be improved and the dominant discourse of women who present with pelvic pain as being hysterical women with painful periods needs to change. Thirdly, the stigma and judgement of lay people needs changing as the attitudes towards this disease and some of the diets and other restrictions women do to help manage their symptoms is poor. The impact of this is substantial leading to isolation and poor mental health. Fourthly, understanding the role of online and other social support groups particularly in this digital age is important, as there needs to be an understanding that these forums are not universally positive and/or necessary at different stages of the journey. Lastly, in attempting to control their lives and their endometriosis women try many different strategies including making decisions around food and restricting alcohol. If the wider social construction of food with relation to socialisation, coping and stress relief is not considered and supported then women with endometriosis are further marginalised.

Future Research

Future research should focus on exploring endometriosis in relation to specific ethnic minority populations. There is very little statistics on endometriosis in these populations in NZ, whether this is because these women do not get diagnosed due to

lack of access or whether it has to do with cultural practices surrounding the discussion of menstruation and as such any abnormalities, or whether because of an entirely different reason which is unknown due to the lack of information. There is evidence that endometriosis is common in Asian populations with a 10% overall incidence rate compared to that of 5% in Western society (Yen, Kim & Lee, 2019), and so this highlights the importance of conducting research with a variety of ethnic groups, as the prevalence of endometriosis varies in different groups. It is therefore important to explore how these women engage with services in NZ where the language, culture and other social understandings of menarche are different to that of their cultural heritage. In NZ the incidence and experience of Māori/Pasifika/Asian women would be highly valued and could provide new information and comparative data with the Pākehā population. This research is important as women's bodies are subjected to a dominant western medical viewpoint that ignores women and their lived experiences, but where of course culture has a large impact on the incidence of illness and how one experiences it. Further, some cultures place different values on and have different cultural practices surrounding food, so whether they used this as a management tool would be insightful.

Another area which could be further investigated is the relationship between medical professionals and the women/patients with endometriosis. This study described many negative experiences between the two parties, where there appeared to be disparities between medical professionals' knowledge and how they viewed women and the experiences that women were having. As such, a piece of research on the relationships between medical professionals and female patients with endometriosis could be beneficial, as looking at the tensions between these groups and the perspectives of both sides, could provide insight into why this is and so and could provide information on how to close the distance and disparities between them, in turn

improving doctor-patient relations and interactions. There have been journal articles which discuss each group of people and their perceptions of endometriosis separately, but there is little literature on the comparison and contrasts between the two groups which would provide a more comprehensive picture. Potentially a study where researchers watch interactions between medical professionals and their patients could provide important information that neither side can see or acknowledge. Further, discussions surrounding the biomedical perspective and utilising both perspectives in ascertaining an appropriate multidisciplinary approach would also be useful.

Lastly, there should be more research conducted on food choices and diets as a form of self-management for women with endometriosis. There should be the investigation of a range of diets on a variety of women with the disease, where there should be the assessment of the effectiveness of this management tool and how best to implement it. What would be more beneficial is the investigation as to whether the stage of endometriosis has any influence over a diets ability to manage symptoms. If there could be the discovery of a current diet that helps symptoms or perhaps new diets which could help a large majority of women with endometriosis, this would be highly beneficial to both doctors and patients, to have assurance that there are tools which can be implemented to help. To best help women we must gain as much knowledge as possible.

Conclusion

This study explored New Zealand women living with endometriosis and how they used food choices and diet as a self-management tool. It was found that living with endometriosis and the consumption of food are so intertwined that it is hard to talk about one without discussing the other due to the effect food has on the symptoms of endometriosis, but also how food can be used to minimise the symptoms of

endometriosis. Food and diet were one strategy women used to take back control, to resist the constant need for pain killers, and to try and come to terms with a disease with no cure. In addition, this research found that the women have struggled or are currently struggling in living with endometriosis due to the profound negative effect it has on all areas of their lives which then impacted on their self-esteem and mental and emotional wellbeing. The most noteworthy findings in this study were the themes of self-sacrifice, luck and gratitude, and positive experience. Women discussed self-sacrifice in relation to sex, relationships, and socialising (sacrificing their health and pain levels to maintain strong intimate and social relationships). Women used the terms of luck and gratitude in certain stages of their journey with endometriosis. They discussed being lucky to have found and received help from a medical professional when they had never had this experience before, and thankful for the support of their parents and their partners. Despite the overwhelming and debilitating nature of endometriosis, the women in this study view the entirety of their journey as positive as it led them to be the strong, healthy and independent women that they are today. These findings are not something that has been highlighted in the literature on endometriosis to date providing important insights into the lived experiences of these women. Other key findings included the long and difficult journey to diagnosis, lack of education, treatment, debilitating pain, over-medicalisation, all of which have been highlighted in previous qualitative research on endometriosis. This study did highlight how often women used self-management strategies such as diet, the effectiveness of certain dietary measures, and how this made them feel. There did not appear to be one diet that all the women found useful at all times as, but there were common approaches such as FODMAP diet, gluten free, dairy free, and limited or no meat. This information found could help medical professionals in their treatment of women, realising that the current methods of providing stronger and

stronger pain killers are not effective enough. Women are still severely suffering and at times do things they know will induce that suffering in themselves so that they can enjoy moments in their lives (eating cake or having a drink or enduring sex). This research continues to highlight the negative experiences of the women with endometriosis within the medical field. Women believe that being badly treated and neglected is the norm, feeling lucky when this is not the case, with the hopes that the medical field will introduce protocols to educate and prevent these negative experiences from happening in the future.

References

Abbott, J. (2016, November 19). Adenomyosis: Sister to endometriosis or distant cousin? *Endometriosis Australia.* Retrieved from https://www.endometriosisaustralia.org/single-post/2016/11/08/Adenomyosis-%E2%80%93-sister-to-endometriosis-or-distant-cousin

Adler, K. W. (2017, April 25). Women are dying because doctors treat us like men. *Marie Claire.* Retrieved from https://www.marieclaire.com/health-fitness/a26741/doctors-treat-women-like-men/

Allen, C., Hopewell, S., & Prentice, A. (2005). Non-steroidal anti-inflammatory drugs for pain in women with endometriosis. *Cochrane Database of Systematic Reviews,* (4). doi:10.1002/14651858.cd004753.pub2

Alvesson, M., & Sköldberg, K. (2018). *Reflexive methodology: New vistas for qualitative research* (3rd ed.). London, United Kingdom: SAGE.

American Society for Reproductive Medicine. (2012). *Endometriosis: A guide for patients.* Retrieved from https://www.reproductivefacts.org/globalassets/rf/news-and-publications/bookletsfact-sheets/english-fact-sheets-and-info-booklets/booklet_endometriosis.pdf

Andrews, T. (2012). What is social constructionism? *Grounded Theory Review, 11*(1). Retrieved from http://groundedtheoryreview.com/2012/06/01/what-is-social-constructionism/

Armour, M., Sinclair, J., Chalmers, K. J., & Smith, C. A. (2019). Self-management strategies amongst Australian women with endometriosis: A national online survey. *BMC Complementary and Alternative Medicine, 19*(1), 17. doi:10.1186/s12906-019-2431-x

Awad, E., Ahmed, H., Yousef, A., & Abbas, R. (2017). Efficacy of exercise on pelvic pain and posture associated with endometriosis: Within subject design. *Journal of Physical Therapy Science, 29*(12), 2112-2115. doi:10.1589/jpts.29.2112

Barak, A., Boniel-Nissim, M., & Suler, J. (2008). Fostering empowerment in online support groups. *Computers in Human Behavior, 24*(5), 1867–1883. doi:10.1016/j.chb.2008.02.004

Berger, R. (2013). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research, 15*(2), 219–234. doi:10.1177/1468794112468475

Black, K., & Fraser, I. S. (2012). Medical management of endometriosis. *Australian Prescriber, 35*(4), 114-117. doi:10.18773/austprescr.2012.050

Bloski, T., & Pierson, R. (2008). Endometriosis and chronic pelvic pain: Unravelling the mystery behind this complex condition. *Nursing for Women's Health, 12*(5), 382-395. doi:10.1111/j.1751-486X.2008.00362.x

Blumberg, L. (2006). The effect of private health insurance coverage on health services utilisation in New Zealand. *Fullbright New Zealand.* Retrieved from https://www.fulbright.org.nz/wp-content/uploads/2011/12/axford2006_blumberg.pdf

Bohmer, P., Pain, C., Watt, A., Abernethy, P., & Sceats, J. (2001). Maximising health gain within available resources in the New Zealand public health system. *Health Policy, 55*(1), 37–50. doi:10.1016/s0168-8510(00)00107-x

Borghini, R., Porpora, M. G., Casale, R., Marino, M., Palmieri, E., Greco, N., … Picarelli, A. (2020). Irritable Bowel Syndrome-Like Disorders in Endometriosis: Prevalence of Nickel Sensitivity and Effects of a Low-Nickel Diet. An Open-Label Pilot Study. *Nutrients, 12*(2), 341. doi:10.3390/nu12020341

BPA. (2013). Pharmacological management of endometriosis. *Best Practice Journal, 52,* 18-25. Retrieved from https://bpac.org.nz/BPJ/2013/April/docs/bpj52-pages-18-25.pdf

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. Qualitative Research in Psychology, 3 (2). pp. 77-101. doi:10.1191/1478088706qp063oa

Braun, V., Clarke, V., & Hayfield, N. (2019). 'A starting point for your journey not a map': Nikki Hayfield in conversation with Virginia Braun and Victoria Clarke about thematic analysis. *Qualitative Research in Psychology,* 1-22. doi:10.1080/14780887.2019.1670765

Burr, V. (2015). *Social constructionism* (3rd ed.). Sussex, United Kingdom: Routledge, Taylor & Francis.

Camilleri M. (2012). Irritable bowel syndrome: how useful is the term and the 'diagnosis'?. *Therapeutic advances in gastroenterology*, *5*(6), 381–386. doi:10.1177/1756283X12442223

Canterbury District Health Board. (2018). *Re. Official Information Request CDHB 9880.* Retrieved from https://www.cdhb.health.nz/wp-content/uploads/417971df-cdhb-9880-various-wait-times-for-public-health-services.pdf

Chahl, L. A. (1996). Opioids: Mechanisms of action. *Australian Prescriber, 19,* 63-65. doi:10.18773/austprescr.1996.063

Chron's & Colitis Foundation. (2019). *IBS vs. IBD.* Retrieved from https://www.crohnscolitisfoundation.org/what-is-ibd/ibs-vs-ibd

Clarke, V., & Braun, V. (2018). Using thematic analysis in counselling and psychotherapy research: A critical reflection. *Counselling and Psychotherapy Research, 18*(2), 107-110. doi:10.1002/capr.12165

Claussen, C. (2018). Men engaging boys in healthy masculinity through school-based sexual health education. *Sex Education,* 1–15. doi:10.1080/14681811.2018.1506914

Conrad, P., Mackie, T., & Mehrotra, A. (2010). Estimating the costs of medicalisation. *Social Science and Medicine, 12,* 1943-1947. doi:10.1016/j.socscimed.2010.02.019

Cooper, D. B., Adigun, R., & Mahdy, H. (2019). *Oral contraceptive pills*. StatPearls Publishing. Retrieved from https://www.ncbi.nlm.nih.gov/books/NBK430882/

Cox, H., Henderson, L., Wood, R., & Cagliarini, G. (2003). Learning to take charge: Women's experiences of living with endometriosis. *Complimentary Therapies in Nursing and Midwifery, 9*(2), 62-68. doi:10.1016/S1353-6117(02)00138-5

Crowe, M., Whitehead, L., Seaton, P., Jordan, J., Mccall, C., Maskill, V., & Trip, H. (2017). Qualitative meta-synthesis: The experience of chronic pain across conditions. *Journal of Advanced Nursing, 73*(5), 1004-1016. doi:10.111/jan.13174

Culley, L., Law, C., Hudson, N., Denny, E., Mitchell, H., Baumgarten, M., & Raine-Fenning, N. (2013). The social and psychological impact of endometriosis on women's lives: A critical narrative review. *Human Reproduction Update, 19*)(6), 625-639. doi:10.1093/humupd/dmt027

Darling, A. M., Chavarro, J. E., Malspeis, S., Harris, H. R., & Missmer, S. A. (2013). A prospective cohort study of vitamins B, C, E and multivitamin intake and endometriosis. *Journal of Endometriosis, 5*(1), 17-26. doi:10.5301/je.5000151

Day, A. (2012). *"Yeah but can it kill you?" Understanding endometriosis in the Atlanta area.* [Master's Thesis, Georgia State University]. Retrieved from https://scholarworks.gsu.edu/cgi/viewcontent.cgi?article=1069&context=anthro_theses

Dearing, A. R. (2019). *Redemption or contamination: Reviewing the illness narratives of the chronically sick and their support systems* [Honours Thesis, University of Tennessee]. Semantic Scholar. https://pdfs.semanticscholar.org/f289/7e10b0e3a7aa32a82a6e18ca7e7326b13032.pdf

De Graaff, A. A., D'Hooghe, T. M., Dunselman, G. A., Dirksen, C. D., Hummelshoj, L., & Simoens, S. (2013). The significant effect of endometriosis on physical, mental and social wellbeing: Results from an international cross-sectional survey. *Human Reproduction, 28*(10), 2677–2685. doi:10.1093/humrep/det284

Delormier, T., Frohlich, K. L., Potvin, L. (2009). Food and eating as a social practice – understanding eating patterns as social phenomena and implications for public health. *Sociology of Health and Illness, 31*(2), 215-238. doi:10.111/j.1467-9566.2008.01128.x

Denny, E., & Mann, C. H. (2008). Endometriosis and the primary care consultation. *European Journal of Obstetrics and Gynecology, 139*(1), 111-115. doi:10.1016/j.ejogrb.2007.10.006

Duffy, J. M., Arambage, K., Correa, F. J., Olive, D., Farquhar, C., Garry, R., … Jacobson, T. Z. (2014). Laparoscopic surgery for endometriosis, (4). *Cochrane Database of Systematic Reviews.* doi:10.1002/14651858.cd011031.pub2

East, M. (2017). Mirena or Jaydess? Retrieved from https://nzendo.org.nz/esig-ask-an-expert/

Ek., M., Roth, B., Ekström, P., Valentin, L., Bengtsson, M., & Ohlsson, B. (2015). Gastrointestinal symptoms among endometriosis patients-A case-cohort study. *BMC Women's Health, 15*(59), 1-10. doi:10.1186/s12905-015-0213-2

Endometriosis New Zealand (2019a). *Diagnosis of Endometriosis.* Retrieved from https://nzendo.org.nz/endo-information/

Endometriosis New Zealand (2019b). *Endo Treatment.* Retrieved from https://nzendo.org.nz/endo-treatment/

Endometriosis New Zealand (2019c). *Fertility and Endometriosis.* Retrieved from https://nzendo.org.nz/fertility-and-endometriosis/

Endometriosis New Zealand (2019d). *Managing Endo.* Retrieved from https://nzendo.org.nz/managing-endo/

Endometriosis UK. (2019). *Pain Relief for Endometriosis.* Retrieved from https://www.endometriosis-uk.org/pain-relief-endometriosis

Esposito, J. (2014). Pain is a social construction until it hurts. *Qualitative Inquiry, 20*(10), 1179–1190. doi:10.1177/1077800414545234

Facchin, F., Barbara, G., Saita, E., Mosconi, P., Roberto, A., Fedele, L., & Verecelinni, P. (2015). Impact of endometriosis on quality of life and mental health: Pelvic pain makes the difference. *Journal of Psychosomatic Obstetrics and Gynecology, 36*(4), 135-141. doi:10.3109/0167482X.2015.1074173

Facchin, F., Saita, E., Barbara, G., Dridi, D., & Vercellini, P. (2018). "Free butterflies will come out of these deep wounds": A grounded theory of how endometriosis affects women's psychological health. *Journal of Health Psychology, 23*(4), 538-549. doi:10.1177/1359105316688952

Family Planning (2015). *Taking your pill continuously.* Retrieved from https://www.familyplanning.org.nz/news/2015/taking-your-pill-continuously

Family Planning (2019). *Intra Uterine Device.* Retrieved from https://www.familyplanning.org.nz/advice/contraception/intra-uterine-device-iud

FigureNZ (2020). Obstetricians and gynaecologists in New Zealand. Retrieved from https://figure.nz/chart/pyDdDh4tmdRHSX7B-YR9VpK1So6ZxYdVm

Findlay, D. (1992). The medical gaze: Medical models, power, and women's health. *Atlantis: Critical Studies in Gender, Culture, and Social Justice, 18*(1-2), 104-124. Retrieved from https://journals.msvu.ca/index.php/atlantis/article/view/5173/4371

Fine, P. G. (2011). Long-term consequences of chronic pain: Mounting evidence for pain as a neurological disease and parallels with other chronic disease states. *Pain Medicine, 12,* 996-1004.

Fjerbaek, A., & Knudsen, U. B. (2007). Endometriosis, dysmenorrhea and diet-What is the evidence? *European Journal of Obstetrics and Gynecology and Reproductive Biology, 132*(2), 140-147. doi:10.1016/j.ejogrb.2006.12.006

Fraser, I. S., Franzcog, C. (2008). Recognising, understanding and managing endometriosis. *Journal of Human Reproductive Sciences, 1*(2), 56-64. doi:10.4103/0974-1208.44112

Gergen, K. J. (1973). Social psychology as history. *Journal of Personality and Social Psychology, 26*(2), 309–320. doi:10.1037/h0034436

Gilmour, J. A., Huntington, A., & Wilson, H. V. (2008). The impact of endometriosis on work and social participation. *International Journal of Nursing, 14*(6), 443-448. doi:10.1111/j.1440-172x.2008.00718.x

Govender, V., & Penn-Kekana, L. (2008). Gender biases and discrimination: a review of health care interpersonal interactions. *Global Public Health, 3*(sup1), 90–103. doi:10.1080/17441690801892208

Grace, V. M. (1995). Problems women patients experience in the medical encounter for chronic pelvic pain: A New Zealand study. *Health Care for Women International, 16*(6), 509–519. doi:10.1080/07399339509516206

Grace, V. M., & MacBride-Stewart, S. (2007). 'Women get this': Gendered meanings of chronic pelvic pain. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine, 11*(1), 47-67. doi:10.1177/1363459307070803

Guillemin, M., & Gillam, L. (2004). Ethics, Reflexivity, and Ethically Important Moments. *Research Qualitative Inquiry, 10*(2), 261-280. doi:10.1177/1077800403262360

Hållstam, A., Stålnacke, B., Svensén, C., & Löfgren, M. (2018). Living with painful endometriosis – a struggle for coherence. A qualitative study. *Sexual and Reproductive Healthcare, 17*, 97-102. doi:10.1016/j.srhc.2018.06.002

Haislet, C. A. (2019). *Endometriosis.* Retrieved from: https://diamondobgyn.com/gynecologists-edina-mn/endometriosis/

Halpern, G., Schor, E., & Kopelman, A. (2015). Nutritional aspects related to endometriosis. *Revista da Associação Médica Brasileria, 61*(6), 519-523. doi:10.1590/1806-9282.61.06.519

Horton, J., Macve, R., & Struyven, G. (2004). Qualitative Research: Experiences in Using Semi-Structured Interviews. In C. Humphrey & B. Lee (Eds.) *The Real Life Guide to Accounting Research: A Behind the Scenes View of Using Qualitative Research Methods* (pp. 339–357). Elsevier. doi:10.1016/b978-008043972-3/50022-0

Hudelist, G., Fritzer, N., Thomas, A., Niehues, C., Oppelt, P., Haas, D., … Salzer, H. (2012). Diagnostic delay for endometriosis in Austria and Germany: causes and

possible consequences. *Human Reproduction, 27*(12), 3412–3416. doi:10.1093/humrep/des316

Hummelshøj, L. (2005). *Endometriosis: the patients' perspective. Women's Health Medicine, 2*(1), 24. doi:10.1383/wohm.2.1.24.58874

Hummelshøj, L. (2017). Endometriosis: An old problem without a current solution. *Acta Obstetricia et Gynecologia Scandinavica*, *96*(6), 779-782. doi:10.1111/aogs.13075

Huntington, A., & Gilmour, J. A. (2005). A life shaped by pain: Women and endometriosis. *Journal of Clinical Nursing, 14*(9), 1124–1132. doi:10.1111/j.1365-2702.2005.01231.x

Hurwitz, L. B., Lauricella, A. R., Hightower, B., Sroka, I., Woodruff, T. K., & Wartella, E. (2017). "When you're a baby you don't have puberty": Understanding of puberty and human reproduction in late childhood and early adolescence. *Journal of Early Adolescence, 37*(7), 925-947. doi:10.1177/0272431616642323

Issa, B., Ormesher, L., Whorwell, P. J., Shah, M., & Hamdy, S. (2016). Endometriosis and irritable bowel syndrome: A dilemma for the gynaecologist and gastroenterologist. *The Obstetrician and Gynaecologist, 18,* 9-16. doi:10.1111/tog.12241

Jankovich, E., & Watkins, A. (2017). Case study: The low FODMAP diet reduced symptoms in a patient with endometriosis and IBS. *South African Journal of Clinical Nutrition, 30*(4), 32-36. Retrieved from http://www.sajcn.co.za/index.php/SAJCN/article/view/1301

John Hopkins Medicine. (2019). *Endometriosis.* Retrieved from https://www.hopkinsmedicine.org/health/conditions-and-diseases/endometriosis

Johnston-Robledo, I., & Chrisler, J. C. (2011). The menstrual mark: Menstruation as social stigma. *Sex Roles, 68*(1-2), 9-18. doi:10.1007/s11199-011-0052-z

Johnston-Robledo, I., & Stubbs, M. L. (2012). Positioning periods: Menstruation in social context: An introduction to a special issue. *Sex Roles*, *68*(1), 1-8. doi:10.1007/s11199-012-0206-7

Jones, C. E. (2016). The pain of endo existence: Toward a feminist disability studies reading of endometriosis. *Hypatia: A Journal of Feminist Philosophy*, *31*(3), 554-571. doi:10.1111/hypa.12248

Jones, C. E. (2015). Wandering wombs and ‘‘female troubles’’: The hysterical origins, symptoms, and treatments of endometriosis. *Women's Studies, 44*(8), 1083–1113. doi:10.1080/00497878.2015.1078202

Jones, G., Jenkinson, C., & Kennedy, S. (2004). The impact of endometriosis upon quality of life: A qualitative analysis. *Journal of Psychosomatic Obstetrics and Gynaecology, 25*(2), 123-133. doi:10.1080/01674820400002279

Jones, G., Kennedy, S., Barnard, A., Wong, J., & Jenkinson, C. (2001). Development of an endometriosis quality-of-life instrument: The Endometriosis Health Profile-30. *Obstetrics and Gynecology*, *98*(2), 258-264. doi: 10.1016/s0029-7844(01)01433-8

Kaur, R., Kaur, K., & Kaur, R. (2018). Menstrual hygiene, management, and waste disposal: Practices and challenges faced by girls/women of developing countries. *Journal of Environmental and Public Health*, 1-9. doi:10.1155/2018/1730964

Kortlever, T., Hebblewaithe, C., Leeper, J., O'Brien, L., Mulder, C., & Gearry, R. B. (2016). Low FODMAP diet efficacy in IBS patients: What is the evidence and

what else do we need to know? *The New Zealand Medical Journal, 129*(1442), 79-87. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/27657161

Kralik, D., Koch, T., Price, K., & Howard, N. (2004). Chronic illness self-management: taking action to create order. *Journal of Clinical Nursing, 13*(2), 259–267. doi:10.1046/j.1365-2702.2003.00826.x

Kralik, D., Loon, A., & Visentin, K. (2007). Resilience in the chronic illness experience. *Educational Action Research, 14*(2), 187-201. doi:10.1080/09650790600718035

Kristjansdottir, O. B, Stenberg, U., Mirkovic, J., Krogseth, T., Ljoså,, T. M., Stange, K. C., & Ruland, C. M. (2018). Personal strengths reported by people with chronic illness: A qualitative study. *Health Expectations, 21*(4), 787-795. doi:10.1111/hex.12674

Kundu, S., Wildgrube, J., Schippert, C., Hillemanns, P., & Brandes, I. (2015). Supporting and inhibiting factors when coping with endometriosis from the patients perspective. *Geburtshilfe Frauenheilkd, 75*(5), 442-469. doi:10.1055/s-0035-1546052

Kupiec, K. (2019). Missing from research: Exposing the deficit in knowledge and research of endometriosis in women's health. *Dissenting Voices, 8*(1), 79-92. Retrieved from https://digitalcommons.brockport.edu/cgi/viewcontent.cgi?article=1091&context=dissentingvoices

Lafrance, M. N., & Wigginton, B. (2019). Doing critical feminist research: A feminism and psychology reader. *Feminism and Psychology,* 1-19. doi:10.1177/0959353519863075

Lovkist, L., Boström, P., Edlund, M., & Olovsson, M. (2016). Age-related differences in quality of life in Swedish women with endometriosis. *Journal of Women's Health, 25*(6), 646-653. doi:10.1089/jwh.2015.5403

Mahon, T., Tripathy, A., & Singh, N. (2015). Putting the men into menstruation: the role of men and boys in community menstrual hygiene management. *Waterlines, 34*(1), 7-14. doi:10.3362/1756-3488.2015.002

Manwaring, J. (2018, March 8). Let's not normalise period pain. *Medical Observer*. Retrieved from https://jeanhailes.org.au/contents/documents/Resources/Medical__health_articles/Medical_Observer/2018/Period_pain_MO_March.pdf

Marchant-Haycox, S., & Salmon, P. (1997). Patients' and doctors' strategies in consultations with unexplained symptoms: Interactions of gynecologists with women presenting menstrual problems. *Psychosomatics, 38*(5), 440–450. doi:10.1016/s0033-3182(97)71421-x

Marinho, M. C. P., Magalhaes, T. F., Fernandes, L. F. C., Augusto, K. L., Brilhante, A. V. M., & Bezerra, L. R. P. S. (2018). Quality of life in women with endometriosis: An integrative review. *Journal of Women's Health, 27*(3), 399-408. doi:10.1089/jwh.2017.6397

Markovic, M., Manderson, L., & Warren, N. (2008). Endurance and contest: women's narratives of endometriosis. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine, 12*(3), 349–367. doi:10.1177/1363459308090053

Marlow, L. A. V., Waller, J., & Wardle, J. (2015). Barriers to cervical cancer screening among ethnic minority women: A qualitative study. *Journal of Family Planning*

and Reproductive Health Care, 41(4), 248–254. doi:10.1136/jfprhc-2014-101082

McLeod, D., Dew, K., Morgan, S., Dowell, A., Cumming, J., Cormack, D., … Love, T. (2004). Equity of access to elective surgery: Reflections from New Zealand clinicians. *Journal of Health Services Research & Policy, 9*(2), 41–47. doi:10.1258/1355819042349916

Mehedintu, C., Plotogea, M. N., Ionescu, S., & Antonovici, M. (2014). Endometriosis still a challenge. *Journal of medicine and life, 7*(3), 349–357. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4233437/

Meissner, K., Böhling, B., Schweizer-Arau, A. (2010). Long-term effects of traditional Chinese medicine and hypnotherapy in patients with severe endometriosis-a retrospective evaluation. *Complementary Medicine Research, 17*(6), 314-320. doi:10.1159/000322890

Mellado, B. H., Pilger, T. L., Poli-Neto, O. B., Rosa e Silva, J. C., Nogueira, A. A., & Candido dos Reis, F. J. (2019). Current usage of qualitative research in female pelvic pain: A systematic review. *Archives of Gynecology and Obstetrics, 300*(3), 495-501. doi:10.1007/s00404-019-05212-x

Ministry of Health. (2016). *Private Health Insurance Coverage 2011–15: New Zealand Health Survey.* Wellington: Author.

Ministry of Health (2017). *Combined oral contraceptive pill.* Retrieved from: https://www.health.govt.nz/your-health/healthy-living/sexual-health/contraceptive-pills/combined-oral-contraceptive-pill

Mondragon, N. I., & Txertudi, M. B. (2019). Understanding menstruation: Influence of gender and ideological factors. A study of young people's social representations. *Feminism and Psychology, 29*(3), 357-373. doi:10.1177/0959353519836445

Moradi, M., Parker, M., Sneddon, A., Lopez, V., & Ellwood, D. (2014). Impact of endometriosis on women's' lives: A qualitative study. *BMC Women's Health, 14*, 123. doi:10.1186/1472-6874-14-123

Moradi, M., Parker, M., Sneddon, A., Lopez, V., & Ellwood, D. (2019). The Endometriosis Impact Questionnaire (EIQ): A tool to measure the long-term impact of endometriosis on different aspects of women's lives. *BMC Women's Health, 19*(64). doi:10.1186/s12905-019-0762-x

Mortimer, R. C. (2002). *The endometriosis stories: A narrative analysis* (Unpublished Doctoral Dissertation). Massey University, Palmerston North, New Zealand.

Motashaw, N. D., & Dave, S. (2012). *Endometriosis*. Himayatnagar, India: Universities Press.

Mvondo, M. A., Ekenfack, J. D., Essono, S. M., Namekong, H. S., Awounfack, C. F., Laschke, M. W., & Njamen, D, (2019). Soy intake since the prepubertal age may contribute to the pathogenesis of endometriosis in adulthood. *Journal of Medicinal Food, 22*(6), 631-638 doi:10.1089/jmf.2018.0160

National Cancer Institute. (2019). *NCI dictionary of cancer terms*. Retrieved from https://www.cancer.gov/publications/dictionaries/cancer-terms/def/bilateral-salpingo-oophorectomy

New Zealand Government. (2020). *Seeing a Specialist.* Retrieved from https://www.govt.nz/browse/health/gps-and-prescriptions/seeing-a-specialist/

New Zealand Now. (2019). *Healthcare Services.* Retrieved from https://www.newzealandnow.govt.nz/living-in-nz/healthcare/healthcare-services

Nodler, J. L., Harris, H. R., Chavarro, J. E., Frazier, A. L., & Missmer, S. A. (2019). Dairy consumption during adolescence and endometriosis risk. *American Journal of Obstetrics and Gynecology.* doi:10.1016/j.ajog.2019.09.010

Norman, A. (2018). *Ask me about my uterus: A quest to make doctors believe in women's pain.* New York, NY: Hachette Book Group.

O'Hara, R., Rowe, H., & Fisher, J. (2019). Self-management in condition-specific health: a systematic review of the evidence among women diagnosed with endometriosis. *BMC women's health*, *19*(1), 80. doi:10.1186/s12905-019-0774-6

Oxley, T. (1998). Menstrual management: An exploratory study. *Feminism and Psychology, 8*(2), 185-191.

Pfizer Australia. (2016). *Depo-Provera: Consumer Medicine Information.* Retrieved from https://www.medsafe.govt.nz/Consumers/cmi/d/Depo-Provera.pdf

Prentice, A. (2001). Endometriosis. *BMJ (Clinical Research ed.), 323*(7304), 93-95. doi:10.1136/bmj.323.7304.93

Pokrzywinski, R., Soliman, A. M., Chen, J., Snabes, M. C., Taylor, H. S., & Coyne, K. S. (2020). Responsiveness evaluation and recommendation for responder thresholds for Endometriosis Health Profile-30: Analysis of two phase III clincal trials. *Journal of Women's Health, 29*(2), 253-261. doi:10.1089/jwh.2019.7788

Poulin, P. A., Nelli, J., Tremblay, S., Small, R., Caluyong, M. B., Freeman, J., … Stiell, I. G. (2016). Chronic pain in the emergency department: A pilot mixed-methods cross-sectional study examining patient characteristics and reasons for presentations. *Pain Research and Management, 2016,* 1-10. doi: 10.1155/2016/3092391

Reid, R., Steel, A., Wardle, J., & Adaams, J. (2019). Naturopathic medicine for the management of endometriosis, dysmenorrhea, and Menorrhagia: A content analysis. *The Journal of Alternative and Complimentary Medicine, 25*(2), 202-226. doi:10.1089/acm.2018.0305

Roberts, T.-A., Goldenberg, J. L., Power, C., & Pyszczynski, T. (2002). "Feminine protection": The effects of menstruation on attitudes towards women. *Psychology of Women Quarterly, 26*(2), 131–139. doi:10.1111/1471-6402.00051

Rogers, A., Gately, C., Kennedy, A., & Sanders, C. (2009). Are some more equal than others? Social comparison in self-management skills training for long-term conditions. *Chronic Illness, 5*(4), 305–317. doi:10.1177/1742395309350384

Roomaney, R., & Kagee, A. (2016). Salient aspects of quality of life among women diagnosed with endometriosis: A qualitative study. *Journal of Health Psychology, 23*(7), 905-916. doi:10.1177/1359105316643069

Rosenblum, A., Marsch, L. A., Joseph, H., & Portenoy, R. K. (2008). Opioids and the treatment of chronic pain: Controversies, current status, and future directions. *Experimental and clinical psychopharmacology, 16*(5), 405–416. doi:10.1037/a0013628

Rowe, H. J., Hammarberg, K., Dwyer, S., Camilleri, R., & Fisher, J. R. W. (2019). Improving clinical care for women with endometriosis: Qualitative analysis of women's and health professionals' views. *Journal of Psychosomatic Obstetrics and Gynecology,* 1-7. doi:10.1080/0167482X.2019.1678022

Saguyod, S. J. U., Kelley, A. S., Velarde, M. C., & Simmen, R. C. (2018). Diet and endometriosis-revisiting the linkages to inflammation. *Journal of Endometriosis and Pelvic Pain Disorders, 10*(2), 51-58. doi:10.1177/2284026518769022

Santanam, N., Kavtaradze, N., Murphy, A., Dominguez, C., & Parthasarathy, S. (2013). Antioxidant supplementation reduces endometriosis related pelvic pain in humans. *Translational Research: The Journal of Laboratory and Clinical Medicine, 161*(3), 189-195. doi:10.1016/j.trsl.2012.05.001

Schmid-Mohler, G., Yorke, J., Spirig, R., Benden, C., & Caress, A. L. (2019). Adult patients' experiences of symptom management during pulmonary exacerbations in cystic fibrosis: A thematic synthesis of qualitative research. *Chronic illness*, *15*(4), 245-263. doi:10.1177/1742395318772647

Schomacker, M. L., Forman, A., Hansen, K. E., & Ramlau-Hansen, C. H. (2018). Is endometriosis associated with irritable bowel syndrome? A cross-sectional study. *European Journal of Obstetrics Gynecology and Reproductive Biology, 231*, 65-69. doi: 10.1016/j.ejogrb.2018.10.023

Seear, K. (2016). *The makings of a modern epidemic: Endometriosis, Gender and Politics.* New York, NY: Routledge.

Shepherd Works. (2019). *Low FODMAP Diet.* Retrieved from http://shepherdworks.com.au/disease-information/low-fodmap-diet/#wrapper-wmw5541ba420746f

Shohat, E. (1998). Lasers for ladies: Endo discourse and the inscriptions of science. In P. Treichler & L. Cartwright (Eds.), *The Visible Woman: Imaging technologies, Gender, and Science.* (pp. 240- 273.) New York, NY: New York University Press.

Shohat, E. (2006). *Taboo memories, diasporic voices.* Durham, United Kingdom: Duke University Press.

Silverman, M., Nutini, J., Musa, D., Schoenberg, N. E., Albert, S. M. (2009). "Is it half full or half empty?" Affective responses to chronic illness. *Journal of Cross-cultural Gerontology, 24*(3), 291-306. doi:10.1007/s10823-009-9097-7

Sinervo, K. (2013). *When IBS is really endometriosis on the bowel.* Endometriosis Foundation of America. Retrieved from https://www.endofound.org/when-ibs-is-really-endometriosis-on-the-bowel-ken-sinervo-md

Soave, I., Occhiali, T., Wenger, J. M., Pluchino, N., Caserta, D., & Marci, R. (2018). Endometriosis and food habits: Can diet make the difference? *Journal of Endometriosis and Pelvic Pain Disorders, 10*(2), 59-71. doi:10.1177/2284026518773212

Society for Women's Health Research. (2019). *Identifying barriers to care for women with endometriosis.* Retrieved from https://swhr.org/identifying-barriers-to-care-for-women-with-endometriosis/

Sood, R., Foy, R., & Ford, A. C. (2017). Making a positive diagnosis of irritable bowel syndrome. *British Journal of General Practice, 67*(665), 580-581. doi: 10.3399/bjgp17X693857

Soliman, A. M., Fuldeore, M., & Snabes, M. C. (2017). Factors associated with time to endometriosis diagnosis in the United States. *Journal of Women's Health, 26*(7), 788–797. doi:10.1089/jwh.2016.6003

Sommer, M., Hirsch, J. S., Nathanson, C., Parker, R. G. (2015). Comfortably, Safely, and Without Shame: Defining Menstrual Hygiene Management as a Public Health Issue. *American Journal of Public Health, 105*(7), 1302-1311. doi:10.2105/AJPH.2014.302525

Southern Cross Health Insurance. (2019). *Why get health insurance?* Retrieved from https://www.southerncross.co.nz/society/buying-health-insurance/why-get-health-insurance

Spiegel, B. M., Farid, M., Esrailian, E., Talley, J., & Chang, L. (2010). Is irritable bowel syndrome a diagnosis of exclusion?: A survey of primary care providers, gastroenterologists, and IBS experts. *The American Journal of Gastroenterology*, *105*(4), 848–858. doi:10.1038/ajg.2010.47

Stewart, J. (2019). *Four ways exercise can help endometriosis.* https://www.everydayhealth.com/hs/womens-health/exercise-help-endometriosis/

Stewart, M., & Black, K. (2015). Choosing a combined oral contraceptive pill. *Australian Prescriber, 38*(1), 6-11. doi:10.18773/austprescr.2015.002

Stovicek, A. (2018). *Try these eight endometriosis-friendly yoga poses.* Retrieved from: https://www.endofound.org/try-these-eight-endo-friendly-yoga-poses

Strange, J. M. (2000). Menstrual fictions: Languages of medicine and menstruation, c. 1850-1930. *Women's History Review, 9*(3), 607-628. doi:10.1080./09612020000200260

Sweeney, L., Moss-Morris, R., Czuber-Dochan, W., Belloti, L., Kabeli, Z., & Norton, C. (2019). 'Its about willpower in the end. You've got to keep going': A qualitative study exploring the experience of pain in inflammatory bowel disease. *The British Pain Society, 13*(4, 201-213. doi:10.1177/2049463719844539

The Lancet Child & Adolescent Health. (2018). Normalising menstruation, empowering girls. *The Lancet Child & Adolescent Health, 2*(6), 379. doi:10.1016/s2352-4642(18)30143-3

The Pūtaiora Writing Group. (n.d.). *Te Ara Tika Guidelines for Māori Research Ethics: A Framework for Researchers and Ethics Committee Members.* Retrieved from https://www.massey.ac.nz/massey/fms/Human%20Ethics/Documents/Te%20Ara%20Tika%20Guidelines%20for%20Maori%20Research%20Ethics.pdf?45C8FE6C80F21417DF26C61E42ED14DF&fbclid=IwAR2qJmFN8Dozx7LinUFoApLoZGnnRRqZKdfFX5KqI7GSSuVdjMJx-PBckMU

Ussher, J. M. (2006). *Women and psychology. Managing the monstrous feminine: Regulating the reproductive body.* London, United Kingdom: Routledge, Taylor & Francis Group. doi:10.4324/9780203328422

Vannuccini, S., Lazzeri, L., Orlandini, C., Morgante, G., Bifulco, G., Fagiolini, A., & Petraglia, F. (2017). Mental health, pain symptoms and systemic comorbidities in women with endometriosis: A cross-sectional study. *Journal of Psychosomatic Obstetrics and Gynecology,* 39(4), 315-320. doi:10.1080/0167482X.2017.1386171

Velasco, M. (2019, May 29). Endometriosis Diet. *Eighty-Six the Endo.* Retrieved from https://eightysixtheendo.com/endometriosis-diet/

Viganò, D., Zara, F., & Usai P. (2018). Irritable bowel syndrome and endometriosis: New insights for old diseases. *Digestive and Liver Disease, 50*(3), 213-219. doi: https://doi.org/10.1016/j.dld.2017.12.017

Weisberg, E., & Fraser, I. S. (2015). Contraception and endometriosis: Challenges, efficacy, and therapeutic importance. *Open access journal of contraception*, *6*, 105–115. doi:10.2147/OAJC.S56400

Whelan, E. (2007). 'No one agrees except for those of us who have it': Endometriosis patients as an epistemological community. *Sociology of Health and Illness, 29*(7), 957-982. doi:10.1111/j.1467-9566.2007.01024.x

Whitaker, C., Stevelink, S., & Fear, N. (2017). The use of Facebook in recruiting participants for health research purposes: A systematic review. *Journal of Medical Internet Research, 19*(8), e290. doi:10.2196/jmir.7071

White, M. (2001). Receiving social support online: implications for health education. *Health Education Research, 16*(6), 693–707. doi:10.1093/her/16.6.693

Whittemore, R., & Dixon, J. (2008). Chronic illness: The process of integration. *Journal of Clinical Nursing, 17,* 177-187. doi:10.111/j.1365-2702.2007.02244.x.

Widayanti, A. W., Heydon, S., Norris, P., & Green, J. A. (2020). Lay perceptions and illness experiences of people with type 2 diabetes in Indonesia: a qualitative study. *Health Psychology and Behavioural Medicine*, *8*(1), 1-15. doi:10.1080/21642850.2019.1699101

Widdowson, S. (2018, October 19). Endometriosis and Nutrition. *Endometriosis New Zealand.* Retrieved from https://nzendo.org.nz/endo-news/endometriosis-and-nutrition-sara-widdowson/

Wikitoria, T. A. (2004). *The Māori female-her body, spirituality, sacredness and mana: A space within spaces* [Master's Thesis, University of Waikato]. Research Commons. https://researchcommons.waikato.ac.nz/bitstream/handle/10289/10260/thesis.pdf?sequence=3&isAllowed=y

Williams, S. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health and Illness, 22*(1), 40-67. doi:10.1111/1467-9566.00191

Wong, C. L., Ip, W. Y., & Lam, L. W. (2016). *Self-Care Strategies among Chinese Adolescent Girls with Dysmenorrhea: A Qualitative Study. Pain Management Nursing, 17(4), 262–271.* doi:10.1016/j.pmn.2016.04.001

Wood, R., & Johnson, E. T. (2011). *Painkillers.* Retrieved from: https://endometriosis.org/treatments/painkillers/

Wright, K. O. (2019) "You have endometriosis": Making menstruation-related pain legitimate in a biomedical world. *Health Communication, 34*(8), 912-915. doi:10.1080/10410236.2018.1440504

Xu, Y., Zhao, W., Li, T., Zhao, Y., Bu, H., & Song, S. (2017). Effects of acupuncture for the treatment of endometriosis-related pain: A systematic review and meta-analysis. *PLoS ONE 12*(10), e0186616. doi:10.1371/journal.pone.0186616

Yen, C., Kim, M., & Lee, C. (2019). Epidemiologic factors associated with endometriosis in East Asia. *Gynecology and Minimally Invasive Therapy, 8*(1), 4-11. doi:10.4103/GMIT.GMIT_83_18

Young, K., Fisher, J., & Krikman, M. (2015). Women's experiences of endometriosis: A systematic review and synthesis of qualitative research. *Journal of Family Planning and Reproductive Healthcare, 41*(3), 225-234. doi:10.1136/jfprhc-2013-100853

Young, K., Fisher, J., & Kirkman, M. (2018). "Do mad people get endo or does endo make people mad?": Clinicians discursive constructions of medicine and women with endometriosis. *Feminism and Psychology, 0(0),* 1-20. doi:10.1177/0959353518815704

Zur, O., Williams, M. H., Lehavot, K., & Knapp. S. (2009). Psychotherapist self-disclosure and transparency in the internet age. *Professional Psychology: Research and Practice, 40*(1), 22-30. doi:10.1037/a0014745

Appendices

Appendix A: Information Sheet

INFORMATION SHEET

The information sheet was provided to the people running the Facebook groups that I wanted to recruit from to provide them with information about the study. It was also provided to people wishing to participate in this study. The information sheet begins below.

Kia Ora, Talofa lava, Mālō e leilei, Nī hau, Namaste, Bonjour, and Hello.

My name is Kimberley Templeton and as part of my MA (by thesis) degree in Psychology I am doing some research on women's diagnosis of and experiences with endometriosis, and the role food/diet plays in managing and living with this disease.

Endometriosis is so individualized in terms of presentation, diagnosis and management and it is not well understood even in the medical profession, meaning that women often find unique ways to help manage the disease. It is therefore important for research to explore women's experiences of this disease. This research focuses on the effects of diet on managing and living with endometriosis for women who have been diagnosed with this disease for at least three years. This research will ask about the diagnosis journey, current symptoms and both past and current experiences of living with endometriosis. Attention will be given to managing the disease, with a particular focus on diet-related management.

You are invited to take part in this study. Whether you decide to take part or not is your choice. If you do not want to take part, you do not have to give a reason.

This Information Sheet will help you decide if you want to participate in this study. It outlines why I am doing the study, what involvement is needed from you if you wish to participate, any benefits or risks there may be, and what would happen at the conclusion of the study. You do not have to decide immediately whether you would or would not like to participate in this study. Before you decide, you may want to discuss the study with other people, such as family, whānau, friends, or health providers, and you may and are encouraged to do so.

This information Sheet is three pages long. Please take the time to read and understand all the pages of the Information Sheet before providing consent. If you agree to take part in this study, you will be asked to sign a consent form.

Who can participate in this project?

Specific endometriosis support groups on Facebook will be selected to approach for this study. Facebook group administrators will be contacted directly for permission to post the advertisement for recruitment of participants from their Facebook page. Any people who are interested will have been directed to (from the advertisement) to directly contact the researcher via private message on Facebook or email on their intention to participate. Only the researcher will know who participated in the study.

Inclusion Criteria
Female individuals who are aged eighteen years or older, and who have been surgically diagnosed by a gynaecologist with endometriosis for a minimum of three years. Participants must also be residing in New Zealand at the time of this study.

Women of any ethnicity are invited to participate however, the interviews will be conducted in English.
I reside in Auckland so face-to-face interviews will be conducted in Auckland, but participants can reside anywhere in New Zealand if you are happy to be interviewed on the phone or via skype.

If you participate what will you be required to do?

If you decide to participate in this study, you will be asked to participate in two semi-structured interviews, approximately two weeks apart, either in person or via skype or phone. Each interview should take no longer than one hour to complete, however it will depend on the amount of information you wish to share. Between each interview you will be asked to fill in a food diary of food choices you have made in the past and the present in an attempt to manage your endometriosis symptoms. This food diary can be done at your own discretion but allowing approximately ten minutes every day or two to reflect on your choices and to write down anything that you can think of should be suffice. You are free to withdraw from the research at any time during data collection. You may bring whanau, friends or other support people to your interviews.

In the first interview you will be asked questions relating directly to your journey and experience of living with endometriosis. We will create a timeline of your journey with endometriosis together. In the second interview there will be a focus on your management of endometriosis symptoms through the use of diet and food and any other remedies you may have tried. In between the two interviews I will ask you to complete a food diary. In this food dairy you would write in a table any alterations in diet, any change in symptoms and how you are feeling, this can be reflections made about food choices in both the past and the present. This food diary can be done in a notebook, on a Microsoft Word document or on the memo/notepad application on their phone, which they can then email to me before the second interview or they can give it to me in person at their second interview. We will then discuss the food diary in the second interview, where I will use the food diary as a prompt to discuss how you feel the food/diet changes have effected your symptoms. We will add to the timeline any diet changes you have tried over the years. As such, the interviews could take more or less time depending on the information you wish to discuss. However, you do not have to discuss anything you do not want to.

For participating in this research project, participants will be offered a koha of a $50 grocery voucher for providing their time, experiences and knowledge.

There is no anticipated harm or discomfort intended as part of this research, however I do acknowledge that this disease can be difficult to live with due to its many challenges. However, I am interested in your experiences with endometriosis, with a particular focus on diet, and you will not have to discuss anything you do not wish to. I do understand that your journey will not have been an easy one and so I am seeking participants who have lived with this disease for a minimum of three years, due to the increased likelihood of having come to terms living with and managing such a disease.

Data Management

The information/data that you provide in each interview will be recorded on a voice recorder and will initially only be accessible by the researcher and supervisor directly involved in this study. Once the information has been transcribed (put into written form) for each interview, you will be provided with a copy of these transcriptions, which you may edit and make adjustments to if you feel necessary.

After you have read through each transcript, a Transcript Release Authority Form will be provided for you to sign if you wish, allowing the researcher to use the information from the transcription, as by signing you will be indicating that you accept the transcript and the usage of such.

Once the verbal information has been transcribed, it will then be coded for themes and ideas present throughout the interview. All identifying information will be removed from the transcript, the data, and the write-up of the research, in order to ensure that it is not possible for you to be identified. The qualitative data gained from the interview will only be accessible by the researcher and supervisor initially, however, there is the possibility that your responses may be used in research publications.

Any personally identifying information that you provide will be stored on a password-protected computer and hard-drive until the research is complete in February 2020, and then it will be deleted. Data will be deidentified (anonymous) so you will not be able to be identified. These deidentified transcripts and food diaries will be kept in the safe-keeping of the supervisor until the research is completed. However, it should be noted that whilst every endeavor will be undertaken to ensure your confidentiality, this cannot be guaranteed.

A summary of the project's findings will be available once the project is complete in February 2020. I will send this to you if you request this.

Participant's Rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- *decline to answer any particular question;*
- *withdraw from the study at any time up until the data from both interviews has been collected;*
- *ask any questions about the study at any time during participation;*
- *provide information on the understanding that your name will not be used;*
- *be given access to a summary of the project findings when it is concluded.*
- *ask for the recorder to be turned off at any time during the interview.*

Project Contacts

You are invited to contact either the researcher or supervisor if you have any questions about the study.

Researcher:
Kimberley Templeton
Ktempleton77@hotmail.com

Supervisor:
Dr Kathryn McGuigan
School of Psychology
Massey University
Private Bag 102-904
North Shore
Auckland 0745
Tel +64 9 414 0800 ext 43115
K.Mcguigan@massey.ac.nz

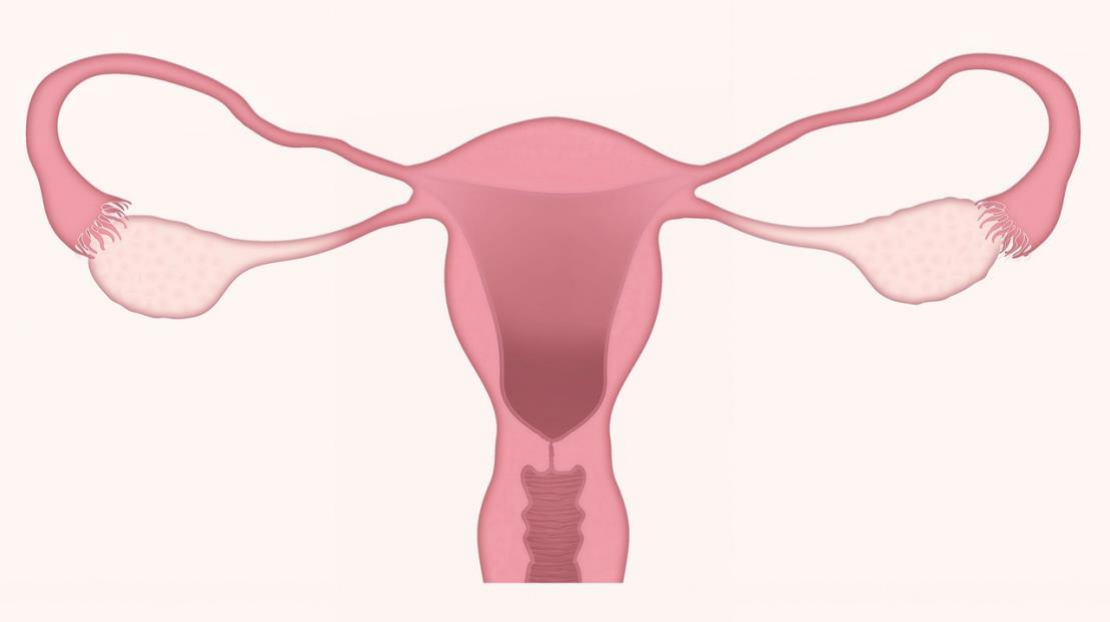
This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 19/35. If you have any concerns about the conduct of this research, please contact Associate Professor David Tappin (Committee Chair), Massey University Human Ethics Committee: Northern, email humanethicsnorth@massey.ac.nz.

Appendix B: Advertisement

Endo Warriors! Share your story, be heard!

I am doing my Masters at Massey University and I am looking to talk with women (18+ years) who have been surgically diagnosed with endometriosis by a gynaecologist. You must have been living with the disease for a minimum of three years and be residing in New Zealand to participate. I am particularly interested in how you have experimented with diets in the management of your disease.

You will be required to participate in two interviews spaced about 2 weeks apart and complete a food/symptom diary. Both interviews should take no longer than an hour. The interviews can be in person, via skype or on the phone, so you can live anywhere in New Zealand.



If you are interested in participating and would like to know more, please contact Kimberley Templeton via private message on Facebook, or by email on ktempleton77@hotmail.com
I will forward you a more detailed information sheet about this research project at this time.
Your participation would be much appreciated!

Appendix C: Consent Form

PARTICIPANT CONSENT FORM

I have read, or have had read to me in my first language, and I understand the Information Sheet. I have had the details of the study explained to me, any questions I had have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from the study at any time.

1. I agree to the interview being sound recorded (please circle): Y / N
2. I wish to have the written transcripts of my recordings returned, so I have the opportunity to read and edit these (please circle): Y / N
3. I agree to participate in this study under the conditions set out in the Information Sheet (please circle one): Y / N
4. I agree to the deidentified information I provide being stored until the completion of the study (please circle): Y / N

Declaration by Participant:

I _____ hereby consent to take part in this study.
[print full name]

Signature: _____ Date: _____

If you have requested a summary of the research findings or to have your recording returned to you for editing, please provide contact information below:

Either: Your address:

_____

_____

OR: Your e-mail address:

_____

_____

Appendix D: Participants Experiences

Sally: Sally suffered from "debilitating" periods from the age of thirteen, where she was diagnosed with Polycystic Ovary Syndrome (PCOS). This is despite having a family member-her sister-who had been diagnosed with endometriosis previously, and her mother attempting to advocate for her, asking the doctor if it could be endometriosis. The doctor strongly disagreed that it could be endometriosis as she was too young. Eventually Sally's mother managed to get her a referral to a gynaecologist in the private system where endometriosis was found, and so she was diagnosed with stage two endometriosis in November 2017 at age seventeen. Sally is on numerous medications, has had three laparoscopic surgeries, and she has also tried alternative methods such as physiotherapy and made diet changes in an attempt to alleviate symptoms. She has had both good and bad experiences in the workforce and also as a patient in the medical profession. She views living with endometriosis and her experiences with it as something she has no control over and so she does not waste her energy and mental and emotional health ruminating on it.

Tania: Tania had her first period at the young age of ten, and from then she had lengthy, erratic, painful periods, with excessive bleeding. At age twelve she started getting debilitating pelvic pain randomly throughout the month, which occurred when she was ovulating. The doctors told her that she was only in such pain because she was very young to be getting her period, and just plied her with paracetamol which did not help. Between the ages of ten and twelve she was put on the contraceptive pill. She developed anaemia and had to drop out of boarding school. Only at the age of sixteen did a doctor take her seriously, notice that her symptoms were abnormal, perform a laparoscopy and diagnose her with endometriosis. At age twenty the symptoms were so severe that she had an extensive laparoscopy, however a fibroid was found on her uterus

which doctors dismissed and let grow in her body until she was forty-one. This fibroid got so big that it became cancerous and Tania had to have a full hysterectomy. In spite of having a full hysterectomy, Tania has food intolerances related to her endometriosis which still plague her and cause symptoms such as pelvic pain and nausea.

Chloe: Chloe got her first period when she was twelve which she experienced as painful but "just dealt with it". Chloe found it extremely painful to use tampons but had to do so because of her swimming. When she was fifteen, she started experiencing pelvic pain randomly throughout the month rather than just with her periods, and ever since there has been an ever-present chronic pain that will not go away, often accompanied by other symptoms. After a multitude of invasive tests, her gynaecologist thought it may be endometriosis and so did a laparoscopy, found signs of endometriosis and then did not treat it, claiming that she did not have it. Instead Chloe was put on the Mirena, which exacerbated her symptoms. Years later, Chloe had a second surgery where it was confirmed that she had endometriosis. Chloe is currently on a "cocktail of drugs" and has tried other medical treatments as well as self-management tools such as alteration of diet, which have no effect on her symptoms. It impacts her functioning in everyday life, however, Chloe has been made to feel on many occasions that it is all in her head and that she is being dramatic, despite the significant impact on her life. Chloe has also recently been diagnosed with ehlers danlos syndrome and has to manage the two conditions.

Sonia: Sonia got her first period between the age of thirteen and fourteen and from then on, her periods were very irregular and were accompanied by other hormonal issues such as acne. At the age of fifteen this was attributed to and diagnosed as PCOS and so she was put on the pill, which made her periods regular and appeared to have fixed some of her hormonal issues. In her mid-twenties however, Sonia started to

experience extremely heavy periods and severe pelvic pain randomly throughout the month which prevented her from doing things. Her endocrinologist ignored her concerns, telling her it was PCOS and that she was fine, gave her some heavy painkillers and attributed the increased pain and heavy flow to the fact that she was aging. Between the age of thirty-two and thirty-three Sonia came off the pill as her husband and herself were trying to have a baby. This unleashed a lot of problems and symptoms of endometriosis and when she went to her doctor, they advised her to try dieting which did not work. A gynaecologist told her she did too much high-intensity exercise and that's why she was experiencing those symptoms. Sonia was exposed to a variety of medical tests and then was told she had a UTI (despite negative test results) and was put on four rounds of antibiotics which did nothing. After much testing and many doctors and specialists, Sonia was referred to a gynaecologist who performed a laparoscopy and diagnosed her as having stage 3 and ½ endometriosis in 2017 at age thirty-three. The pain and other symptoms continued and so another gynaecologist diagnosed her with adenomyosis in July 2018 and performed another laparoscopy in September 2019, finding the endometriosis had grown back. Sonia's social life has been affected as has her enjoyment of exercise, her work-life, her ability to have children, her sex life and relationships, and the relationships she has with female family members. She has tried numerous medications, surgeries and diets to attempt to manage the symptoms. Sonia is currently trying to decide whether or not she wants a full hysterectomy.

Megan: From Megan's first period she experienced debilitating pain and nausea, much to the disbelief of both parents and doctors. Megan was made out to be a hypochondriac as others thought that all periods should be painful. As such it took four years for her to even get looked at for these symptoms by a doctor, and once she had

there were constant visits to try and ascertain the cause. At eighteen years old, Megan was officially diagnosed with endometriosis via laparoscopy which helped with symptoms for approximately one year, and after two years Megan had her second surgery where nothing was found this time. Megan could not take any oral contraceptives as she suffered from migraines, and the only hormonal control she could take was the Depo-Provera which caused extreme weight gain and mood swings. Megan takes strong painkillers instead to help with her chronic pain, has had multiple laparoscopic surgeries and has only tried minimal self-management methods. Megan's endometriosis has affected her relationships, sex-life, social life, relationships with her parents and her work-life. Megan has now come to terms with her endometriosis diagnosis and despite being worried about its progression she has accepted that it is not curable.

Susan: Susan got her first period at age twelve and although she does not recall the start of her symptoms, she recalls always having them. Painful, bad periods have always been a fact of life for her, and she was put on the pill when she was fourteen. Susan's mother also had heavy, painful periods but when she got pregnant with Susan her symptoms disappeared -although she was never diagnosed with endometriosis, this is a possibility. Susan was in such severe pain that she used to inflict pain elsewhere on her body in an attempt to distract herself. However, she was only given Panadol and on the odd occasion a pethidine injection to help the pain. Susan's mother was a massive advocate for her getting the correct medical treatment. At twenty years old Susan had her first laparoscopy where they found endometriosis, particularly on her bladder. Susan has developed pre-cancer cells on her cervix on numerous occasions, and on occasion she gets abnormal smear results. Endometriosis impacted on Susan's schooling, on her family members who watched her suffer, on her ability to exercise, her ability to have

children, her sex-life and relationship with her boyfriend, relationships with friends, and ability to socialise. Susan has tried many medications and had two surgeries whilst also trialling diets. She is currently on the waiting list for another laparoscopy and is considering her future options such as full hysterectomy. Susan takes the view that she could be worse off than she is now, so she just accepts her situation.

Grace: Grace had her first period between the ages of thirteen and fourteen, and from then on struggled with chronic fatigue. Her period felt constant, she was in debilitating pain, so she was put on the pill and had to take six months off school. When she was about fifteen her periods were inconsistent, only having them a couple of times during the year as she was on the pill. This continued until she was seventeen where she was still in such severe pain despite having a high pain tolerance. Grace's Mum was a massive advocate for her in getting taken seriously by doctors and getting the correct treatment. This could perhaps be because of her Mum's knowledge of endometriosis due to a friend of hers having it. After being told it was PCOS (despite negative test results), in 2015 Grace had her first laparoscopy where she was diagnosed with endometriosis at age seventeen. After this, Grace was symptom free for two years. For the past two years her pain has been excruciating and debilitating again. She has tried many medications, alternative methods and has trialled a variety of food and lifestyle choices. Grace's endometriosis symptoms have impacted on her schooling, work, and social life, but she has supportive and understanding friends and family. Grace is currently in the process of trying alternative management methods and feels if she does not find one that helps soon it will be very discouraging. Grace also has concerns about the future in regard to severity of her endometriosis and her fertility.

Rebekah: Rebekah not only has endometriosis, but she also has epilepsy, which has an impact on the treatments and medications she has access to, as some hormones

and painkillers can affect her epilepsy medication, and others exacerbates the chronic migraines that she suffers from. So, in order to help manage all three of her conditions she takes a variety of medications. Her journey with endometriosis started at age nineteen when she had to have an abortion as her epilepsy medication would have impacted on the development of the baby and coming off the medication could be life-threatening for her. From then on everything "snowballed", periods became extremely painful and irregular. At the age of twenty-one the pain was so severe that she had to stop working due to the physical demands of her job that she could not perform. She received surgery in the UK where a large dermoid cyst was found but was left due to it being not urgent. Rebekah was sent home in pain and the cyst kept growing until emergency surgery was performed, and they found the cyst was necrotic and twisted around her ovary. The severe pain moved her back to NZ. Rebekah currently suffers from pain and other symptoms daily and right before her period the pain escalates to unbearable levels. She found a doctor who believed that she had endometriosis but did not want to do anything about it. However, Rebekah advocated for herself, had the surgery and got diagnosed with stage one endometriosis. She was told that her symptoms are not explained by the endometriosis and it must be all in her head. Rebekah tried to pay for private healthcare despite not having insurance, so that she could get adequate care, but it was extremely expensive and so she returned to the public system. However, she has now found specialist gynaecologists in Australia which she is paying for. From them she has received more help in a short amount of time than she has had in total since she was nineteen. Endometriosis impacts on Rebekah's life, her work, her socialising, her sex life and relationship with her boyfriend. She believes she cannot have a life until she gets the surgery from the

specialists in Australia and emphasises the lack of education of the majority of medical professionals she has encountered.

Appendix E: Food Diary Instructions

Food Diary

On the following page is an example of the layout of the food diaries. There will be one table per page, so the participant has plenty of room to comment on past and present changes they have made in their food choices and how this has affected them, and they also have room to continue adding things as they remember. A phone call will be made to the participant one week after the initial interview to see if they are using the diary and to ask if they have any questions. If at this time a date for the second interview has not been made, then this will be arranged on this phone call.

Participants will be offered the choice of the diary being in paper format (and I will provide them with a notepad or small notebook), on a Word document that they can fill in on their computer, or on the memo/notepad application on their phone.

Food Diary

Please use this diary to reflect on your diet and food choice in terms of your endometriosis symptoms and management of these systems. Feel free to make note of any foods, supplements, vitamins or other remedies you ingest or eat to help your symptoms. Also make note of anything you take out of your diet or avoid as much as possible (e.g. coffee, alcohol). This can be something that you try or notice in the time between the interviews or something that you have done for a longer period but maintain during this period. You can also add memories of food changes or diets you have trialled in the past, please just indicate whether you have discarded this change.

Date (if applicable)	**Food change(s) and reason for the change**	**Effects on symptoms**	**Impact on self (feelings, thoughts, experiences)**

E.g 14/06/2019	E.g. cut down on alcohol for about six months. Friend mentioned it had helped menstrual cramps	E.g. cramps lessened dramatically, once a week vs three times	E.g. I felt a lot better in myself, was able to actually go out without worrying too much abo getting sick. However, I could n drink with my friends and so ha to alter when/where I went.
e.g.	Decided to start probiotics again - Getting lots of sore stomachs and diarrhoea and this has helped in the past	No immediate effect but after 3 days I didn't have to use the bathroom as often	Have tried probiotics in the pas forgot to buy them, can get expensive. Maybe if I take thes can keep drinking coffee!

Appendix F: Demographic Information Sheet

Demographic Information.

Name:_____

____

Age:_____

____

Ethnicity (self-identified):_____

____

Place of residence (current city, town or area in New Zealand):

_____

____

Age you received your endometriosis (surgical) diagnosis:

_____

____

Appendix G: Interview Schedule

Interview Schedule.

(The following is a list of possible questions that I may use during the interviews. However, they are semi-structured interviews which I plan to take in a conversational manner and so these questions are prompts rather than set questions.)

Interview 1.

- Please tell me about your journey with endometriosis from the onset until now.
- What symptoms do you experience?
- How have these symptoms effect you and your life?
- Have you noticed any triggers for your flare-ups?
- What has your experience with medical professionals been like throughout your journey?
- How has your condition effected your relationships?
- Describe your treatment plan.
- How do you currently feel about your condition?
  - Is this a stable or changing view?
- Were you ever misdiagnosed, or did you face barriers to receiving endo as your diagnosis?
- Does endometriosis effect your life in terms of work and school, if so, how?
- Is there a particular lifestyle you have adapted to? (Medicine, exercise, alternative medicine, ways of coping).
- What are the benefits and disadvantages to having endometriosis?
- Do you have any future concerns regarding living with endometriosis?

Interview 2.

- How do you manage your symptoms of endometriosis currently?
- Is there a particular lifestyle you have adapted to?
- Have you ever cut out or added certain foods or tried any diets in an attempt to manage your symptoms?
  - How did this effect you?
  - Why did you choose to do this?
- Are there any supplements, or alternative medicines or activities you do in an attempt to manage your symptoms?
  - Why?
  - How does this effect you?
- Is there any food and diet related actions you want to try in the future?
  - Why?
- Have you noticed particular food(s) that triggers your flare-ups?
- What are your thoughts/feelings towards having to alter your diet/food choices for this disease?
- Are there any foods which you should avoid but don't, and why?
- How have you learnt about this information on food and endometriosis?

Potential Food Diary Prompts:

- What was the reasoning behind adapting to this particular food change?
- How did this food change impact on your symptoms of endometriosis?

- Are there any diets or food related changes you wish to try in the future and why?
- Did you try any other alternative treatments/lifestyle choices in addition to these food choices?

Appendix H: Help Sheet

Where to seek help.

If the interviews raise issues that are particularly upsetting, I encourage you to use your personal support systems to talk through these issues. Often reliving the journey can be distressing but sometimes there are benefits of talking with someone who gets it. I do hope that this research may be able to help other women who live with endometriosis, and hopefully my personal experiences with endometriosis can also relate with your experiences.
It can also be useful to talk with your GP or other medical professional that you have a good relationship with.
If you like I can give you the details for The Centre for Psychology at Massey University, Albany, North Shore, Auckland, New Zealand. The Clinic offers Therapy by registered and experienced clinical psychologists.
I personally have found the following resources also to be particularly helpful:

- Endometriosis New Zealand https://nzendo.org.nz/
- Endo Help
- Ask ESIG
- Story Forum

Facebook Support groups that I also find helpful and supportive include:

- Endometriosis New Zealand
- All about Annie's Endometriosis Support Group
- BB's Endo
- Endometriosis Awareness

You can also contact

- The Depression Helpline (0800 111 757)
- Healthline (0800 611 116)
- Lifeline (0800 543 354)
- Samaritans (0800 726 666)
- Youthline (0800 376 633)

Appendix I: Transcript Release Authority

AUTHORITY FOR THE RELEASE OF TRANSCRIPTS

I confirm that I have had the opportunity to read and amend the transcript of the interview(s) conducted with me.

I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research.

Signature: ..... **Date:** .....

Full Name - printed .....

Appendix J: Cultural Consultation Form

School of Psychology
Albany

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Research Ethics
Cultural Consultation Request

Student name: Kimberley Templeton

Student ID: 14170014

Date Seen: 24/04/2019

Research Type: Honours

Psychological Discipline: Other

Research Supervisor(s): Kathryn McGuigan

Research Title: The Role of Diet in Diagnosis, Management and Living with Endometriosis.

Research Aim: To discover what it is like for women to live with endometriosis, and how food effects their condition in terms of their symptoms and subsequent psychological functioning.

Target Participants: Women over 18 years old, with diagnosed endometriosis of at least three years.

Data Collection: Qualitative- Two semi-structured interviews with each participant, in conjunction with a food/symptom diary.

Data Analysis: Thematic analysis, in order to identify key themes present within and across participants interviews.

This project is open to any woman with a diagnosis of endometriosis (endo). Endo affects one in ten girls and women, but every woman's journey is different. Symptoms, diagnostic journey, and management of the disease all vary from woman to woman. However, to get a diagnosis a woman must have surgery. It is difficult to get statistics for endometriosis for both Māori and Pākehā women. The statistics are typically stated as a whole, that is, the incidence rate is for the entire New Zealand population, so I plan to be inclusive of all women with a diagnosis of endometriosis regardless of ethnicity.

Considerations already made with respect to potential Maori participants, and/or any implications of this research for Maori: I have discussions with Kathryn about being culturally aware and safe. On the information sheet and advertisement I will use both Māori and English language in order to incorporate Māori and I will ensure all documents are shown to you as the cultural advisor before I begin recruitment or data collection. Recruitment will happen via social media and on endometriosis support groups. These groups are open to anyone,

of all ethnicities and from all countries, and so of course Māori women are included within this. Further, in order to be inclusive I will give the transcripts back to the participants in order for them to read and approve what they have written, and to clarify and elaborate on aspects of the text if they see fit. Finally, if there is the recruitment of a Māori participant then I will discuss with them that their whanau is invited to come to the interviews and give support if they need, and that if their interview takes place in person (if they so choose) then the interview will take place with sharing of kai at the onset, as is custom to establish whakawhanaungatanga. This will all be done in a way which is respectful to all participants rights, needs and culture.

How Te Tiriti Principles might apply to this research endeavour: To ensure that Māori people have equal opportunity to participate -with this study being online and open to any woman with an endometriosis diagnosis. Ensure that inclusive Māori language is used where appropriate -such as using the Māori greeting "Kia ora" on any paperwork that the participants see. I will refer to NZ endometriosis society website. Their motto is strength through support: Mā te tautoko, ka whai kaha, ka ora. I will also treat the participants as autonomous and as experts on the topic, as they are the ones experiencing the condition -this is essential both for different cultural groups and as this research is being conducted from a feminist perspective, it is also important for all females being interviewed. In conjunction with this, allowing participants to look over and make any clarifications to their transcripts, to ensure they are in control of their knowledge and what is being shared with the world. I should not need to consult with Māori elders on this project as it is not research directed at the Māori population specifically, but is more focused on the condition of endometriosis and how it is experienced in general, but if I did need to I would speak with my supervisor and then discuss this with a cultural advisor at Massey.

Participation- All women including Māori women will be invited to participate, and to give a voice to their experiences, where they will be treated as experts in the topic. Their story and personal experiences will be acknowledged as being important and having value. To gather their stories, I will participate with them by conducting the interviews at a place, time and on a platform, which is convenient to them, and that do not reinforce institutional inequalities. Interviews are semi-structured and so intend to take on a conversational style, meaning that the language will be inclusive, clear and free from jargon so that all participants understand and feel they can participate and conversate with me on an equal level.
Partnership- this project is a partnership with true value, where in cooperation with me there are narratives that will be shared through interviews, which is important to me (as I live with this disease) and also to the other women who live with endometriosis to raise awareness and understanding. This partnership with Māori women also means listening to their story and gathering information on their perspective of living with this disease, whilst protecting them from being stigmatised in terms of their health. In order to develop relationships/whakawhanaungatanga, there will be an informal hui process that I will follow, including taking shoes off at the door, bringing food/kai to share, introduce myself and have an informal discussion to establish connects, introduce my research, if the participant wishes there may be a prayer/karakia prior to the formal start of the interview. After the interview there should be more informal conversation and discussion of the task and the next interview, with perhaps another karakia to close.
Protection- The women who participate in this research will be anonymous and all identifying information will be protected and kept confidential. As such, there will be the use of pseudonyms when discussing each interviewee and all locations, names, and personal identifiers will be cut from the transcript.

Lisa Stewart
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Email: M.Stewart@massey.ac.nz

Appendix K: Summary of Food Diaries

Diets	Tried	Helped	Didn't help/worsened/unsure
FODMAP	4	2	2
High-fibre	1		1
Unprocessed	1	1	
Gluten free	5	4	1
Dairy free	4	2	2
No Onion and garlic	2	2	
Celery Juice detox	1		1
Low/No meat	4	3	1
Fruit/Fructose	2	2	
Fasting	3	2	1 (previously helped)
Elimination/Chemical free Diet	1		1
No salicylates	1	1	
General Healthy Eating	2	2	
Paleo	1	1	
Alkaline Diet	1		1
Plant-based/vegan	1	1	

None of the above diets have been cures, and women still experience symptoms despite these diets helping to decrease some of them. They all 'help' to varying degrees. There are also other individual food intolerances that the women have and avoid but I chose not to include them as they are so specific to each woman. It appears that some women tried diets that once helped but now don't, and it looks like it could be related to progress and severity of their endometriosis.